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MANAGEMENT OF HI-TECH HEALTH CARE IN THE COMMUNITY SETTING

Submitted by Jill Loader for the degree of PhD of the University of Bath 2001.

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Management of Hi-tech Health Care in the Community Setting

Summary

Drugs and health technologies have advanced to such an extent that it is now possible to treat patients at home or in the community with hi-tech health care that would have traditionally required an inpatient admission, for example parenteral nutrition or chemotherapy infusions. In order that patients receiving complex therapies are managed effectively in the community setting shared care agreements have been drawn up between the patient's GP and hospital specialist.

This study used surveys of Health Authorities (HAs) to establish the extent to which different models of shared care have been developed throughout England in response to the government directives EL(91)127 and EL(94)72. It found that in most HA areas some shared care guidelines are in use, mainly for higher cost regimens. A survey of general practitioners (GPs) in South and West Devon was carried out to investigate the merits of one model of shared care. This model was found to provide GPs with a robust framework for sharing care of patients, on complex treatments, with secondary care colleagues.

The arrangements for purchasing and provision of hi-tech healthcare at home (HTHH) under EL(95)5, were studied using questionnaire surveys of HAs, NHS Trusts and commercial providers of HTHH. The effectiveness of EL(95)5 in the delivery of HTHH to patients was evaluated with emphasis on the role of the pharmacist. It was found that there is considerable variation in both the extent to which HTHH is purchased throughout England and the quality of care received by patients. Pharmacists played an important role but were rarely involved with quality assurance of the home care service.

The need for a benchmarking tool to assist in improving the quality of care received by patients receiving HTHH was identified and addressed by the development of a database to facilitate benchmarking and learning from best practice.

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LIST OF ABBREVIATIONS

5-FU	5-fluorouracil
AIDS	Acquired Immunodeficiency Syndrome
ASHP	American Society of Health Systems Pharmacists
ASPEN	American Society for Parenteral and Enteral Nutrition
BAPEN	British Association for Parenteral and Enteral Nutrition
BMA	British Medical Association
BPH	Benign Prostatic Hyperplasia
CHC	Community Health Council
CHCC	Commercial Home Care Company
DMARD	Disease-modifying anti-rheumatoid drug
EL	Executive Letter
EPO	Erythropoietin
FHSA	Family Health Services Authority
GMS	General Medical Services
GP	General Practitioner
HA	Health Authority
HCA	Health Commissioning Authority
HImP	Health Improvement Programme
HIV	Human Immunodeficiency Virus
HPN	Home Parenteral Nutrition
HSG	Health Service Guidance
HTHH	Hi-tech Health Care at Home
IV	Intravenous
JCAHO	Joint Commission on the Accreditation of Health Care Organisations
LMC	Local Medical Committee
LPC	Local Pharmaceutical Committee
NHS	National Health Service
NHSE	National Health Service Executive
NICE	National Institute of Clinical Excellence

NSF	National Service Framework
OHPAT	Outpatient Home Parenteral Antibiotic Therapy
PACT	Prescribing Analysis and Cost
PICC	Peripherally Inserted Central Cannulae
PCG	Primary Care Group
PCT	Primary Care Trust
PMS	Personal Medical Services
SCWG	South and West Devon, Cornwall and Isles of Scilly Shared Care Working Group
TPN	Total Parenteral Nutrition
UK	United Kingdom
US	United States
USA	United States of America

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1 Introduction

1.1 Background

1.1.1 The National Health Service

The National Health Service (NHS) was founded in the United Kingdom in 1948 based upon the principle that it would be available to all, irrespective of means, on the basis of need and that most services would be provided free of charge at the point of use [1]. It is a government-funded organisation and as such is subject to political influences.

The NHS is organised so that patients register with a local doctor, a General Practitioner (GP). GPs are generalists and act as "gatekeepers" to the rest of the NHS. They are responsible for most community-based services and they are, for most patients, the first entry point to the NHS, hence the term "primary care". Practitioners in primary care may refer patients to specialist consultants usually based in hospitals (secondary care) who may then refer on again to doctors in specialist centres (tertiary care). Currently specialists practising from hospitals have little or no experience of community based services. This system is very different to that in the United States and in other countries where private health insurance is the norm and there is no gatekeeper role. The structure of the NHS in England is further described in Chapter 2, Section 2.1.

There has, in recent years, been a movement of health care more traditionally provided in the hospital setting into the community. This is in line with the government agenda of providing care, where appropriate, as close to the patient's home as possible and having decisions about health care made locally [2-5]. In recent reorganisations of the NHS funding has been allocated to primary care organisations so that NHS purchasing decisions can be taken at a local level [2]. The change in emphasis from secondary to primary care has been brought about by increasing costs of hospital care, pressure on hospitals to increase their throughput, advances in technology allowing treatment to be managed at home and the need to optimise quality of life in chronically sick patients [6].

1.1.2 Advances in Therapeutics and Technologies

Advances in two areas have led to the possibility of community-based care for many patients who would traditionally have required a hospital visit or admission [7-13].

Drugs have been developed with better pharmacokinetic and pharmacodynamic profiles which allow for less frequent administration to patients with fewer side effects. Many treatments are now available in formulations that are easier to administer such as via the oral or subcutaneous routes rather than the intravenous route. Once patients are stabilized the monitoring requirements are relatively simple allowing GPs in the community setting to manage the day-to-day care of the patient, sharing care with their hospital consultant colleagues. Examples of such therapies include newer or more complex drugs such as apomorphine, erythropoietin, dornase alpha, interferon, growth hormone, immunoglobulins, octreotide and oral ganciclovir.

Advances in health technologies such as intravenous access devices and infusion pumps and more sophisticated clinical monitoring techniques mean that patients can also be treated at home with therapies which traditionally required a hospital visit or admission because of complex administration techniques such as intravenous (IV) infusions.

Intravenous access devices such as peripherally inserted central cannulae (PICC lines) made of hi-tech materials are associated with less irritation and fewer iatrogenic complications then traditional access devices. Advances in pump technology mean that small ambulatory pumps can be used to administer accurate doses of drugs to patients whilst they go about their everyday lives. They can be programmed to administer complex regimens or have lock out periods when no more drug can be administered and can record accurate histories of drug administration. They can even be reprogrammed over telephone lines using increasingly complex information technology. Implantable pumps with reservoirs have been developed which allow local administration of, for example,

intrathecal or intrarticular infusions. Stability of some drug infusions has improved due to better understanding of agents such as stabilizers and buffers and developments in materials used for containers.

These developments mean that patients are now able to receive home infusion therapy such as parenteral nutrition, continuous chemotherapy or antibiotic infusions safely in their own homes.

1.2 Prescribing of New and Complex Therapies in the Community

General practitioners are often unfamiliar with these newer therapies and administration technologies and will not have the experience of a specialist in the field. The numbers of patients requiring these treatments are small and a general practitioner is unlikely to have come across them before and is unlikely to have more than one patient on their list that requires growth hormone or home parenteral nutrition for example. In order that these therapies can be managed successfully in the community setting a shared care arrangement between the patient's GP and hospital consultant is desirable [14, 15].

Shared care guidelines or protocols are locally agreed management guidelines usually based around a diagnosis or a drug treatment. They seek to overcome communication problems between primary and secondary care through both the development of the guideline and it's content. Guidelines are often developed by a multidisciplinary group. The guidelines seek to give a GP some background on the subject, outline respective responsibilities of members of the healthcare team and highlight monitoring requirements, side effects, interactions etc. The guideline may also specify when it has been agreed that shared care is suitable and the circumstances under which the patient should remain under the care of the secondary care physician.

The specialist may be responsible for one aspect of the patient's care but the GP will be responsible for any other medical problems that may arise whilst the patient is at home and it is important that they are aware of complications that may be attributable to a hi-tech, specialist or new therapy.

It has been recognized that the sharing of care between the hospital consultant and general practitioner is a rational and practical approach to the long-term management of patients with chronic but stabilized illness [16]. This approach has been successful for the management of diseases such as diabetes, epilepsy and hypertension [17, 18]. Providing hi-tech therapies in the community setting has led to the need for much closer working between primary and secondary care practitioners but there have been barriers to this.

Appreciating that discharging patients on hi-tech therapies into the community requires a joint management approach from both secondary and primary care, the NHS Management Executive in 1991 issued a directive in the form of EL(91)127 [19]. This directive contained guidance on the responsibility for prescribing at the hospital/general practitioner interface covering situations where a patient was referred to a hospital specialist who prescribed, an often complex therapy, for a patient until the patient was stabilized. The specialist then asked the general practitioner to take over prescribing and in some cases the monitoring of the patient. EL(91)127 [19] reinforced the basic premise that the doctor who has clinical responsibility for the patient should prescribe and focused on the concept of shared care. It emphasized the need for proper hand-over procedures from hospitals to make sure that the general practitioner was properly informed and could monitor treatment and adjust the dose if necessary suggesting that there should be provision of protocols for treatment.

EL(91)127 [19] lists some of the concerns around interface prescribing. One of the major concerns of GPs is about accepting clinical responsibility for patients on specialist initiated drugs with which they are unfamiliar [19]. The concept of shared care aims to overcome this by a sensible, collaborative approach providing appropriate support, training and good communication channels between the relevant hospital consultant and general practitioner. However, it does not overcome the fact that medico-legally responsibility must always lie with the doctor who signs the prescription [20].

Further guidance from the government in 1994, EL(94)72 [21] asked purchasers to develop a policy on the managed entry of new drugs making use of evidence of their clinical and cost effectiveness. It directed Health Authorities to develop and agree strategies for improving prescribing across the primary/secondary care interface and ensure appropriateness of hospital-led prescribing whilst taking into account the total cost of drugs to the NHS. It advised that formally agreed shared agreements or protocols be used as a tool to formalise the managed entry of new drugs into primary care.

In a recent report on the prescribing of costly medicines the Royal College of Physicians [22] noted that the development of formal shared care guidelines had helped to overcome some of the interface problems around prescribing high cost medicines and recommended that prescribers in secondary care take into consideration the anxiety that those in primary care may have about prescribing certain new medicines.

Some of the difficulties in implementing shared care schemes have led to the development of outreach services from hospitals into the community, the involvement of private health care providers and the development of systems to educate and support GPs involved in caring for patients receiving more complex treatments [14, 18].

1.3 Hi-tech infusions administered in the community

The treatment of patients at home with drugs requiring complex administration techniques such as intravenous infusions of antibiotics, total parenteral nutrition (TPN), chemotherapy, opioid infusions, chelating agents and bronchodilators has become accepted as a safe and effective model of health care [7, 12, 23-25]. For chronically ill patients requiring long term infusions, treatment at home improves their quality of life often enabling them to return to work or school, giving the patients greater opportunity to be with their families and means that they play an active role in their treatment [26, 27]. Few problems have arisen and complication rates have been shown to be low [28-30], possibly, in part due to a decreased risk of nosocomial infections [31].

Patients in the United States commonly receive hi-tech therapies in the community to the extent where even patients relying on artificial respiration are successfully managed in their own home [32]. Hi-tech health care at home (HTHH) has been slower to become accepted in the UK and the rest of Europe [28-30] and other countries such as Japan [33] [34] and Australia [35]. This could be due to a number of factors, amongst them, the way the National Health Service (NHS) is funded [36]. There is no direct cost to a patient or an insurer when a patient is admitted to hospital in the UK and therefore no direct pressure from them to reduce hospital length of stay or frequency of outpatient visits [37].

The numbers of patients being treated with HTHH in England are steadily increasing, as is the cost. Treating these patients at home offers benefits for hospitals in that it enables earlier discharge of patients, frees-up hospital beds and is cost effective in terms of overall efficiency in health delivery [30, 38, 39]. It has however also been argued that if a patient is discharged from a hospital another patient will be admitted or fill that outpatient appointment the total cost to the NHS will increase [40].

With the increasing acceptance of use of hi-tech administration techniques in the community setting during the 1980s and early1990s, concern was raised regarding pressures being placed on GPs to provide the necessary equipment and supplies for these patients. This led to the NHS Executive issuing further guidance in January 1995, in the form of EL(95)5 [41]. This guidance instructed Health Authorities (HAs) to purchase care to support patients at home whose treatments included the delivery of drugs together with other products and equipment needed to administer them. These were typically provided as packages of care including everything that is required for the patient to effectively manage their treatment at home including training of the patient and carer, 24 hour emergency back-up, syringes, needles, infusion pumps, supplies of the drug and often a refrigerator. Examples of packages of care covered by EL(95)5 [41] include Total Parenteral Nutrition (TPN), intravenous antibiotics for cystic fibrosis and chemotherapy infusions.

Prescribing of these services by general practitioners (GPs) was stopped from 1st April 1995. Health Authorities were directed to purchase care for these patients though their commissioning mechanisms. GP prescribing budgets were top-sliced so that money spent on HTHH in primary care could be used by the HAs to commission care for these patients. It made no provision for funding new patients requiring home therapy, or patients who were receiving infusions at home which were not being prescribed by GPs previously (on FP10 prescriptions). Bryan [15] predicted that EL(95)5 [41] may make the most expensive shared care arrangements flavour of the month on both sides of the primary/secondary care prescribing divide.

There have been two major reports focusing on the purchasing of HTHH (including enteral nutrition and continuous ambulatory peritoneal dialysis) since the introduction of EL(95)5 [41]. The first was a study commissioned by the North West Regional Health Authority [6] to provide information and guidance to purchasers and ultimately providers of HTHH, to determine key considerations for a purchaser strategy and make recommendations of effective purchasing. This report highlighted the fact that communication between stakeholders was generally poor and that purchasing HTHH is a complex issue for Health Authorities and NHS Trusts due to the possibilities for subcontracting the provision of some services. It was found that all stakeholders acknowledged the importance of implementing appropriate policies and procedures to ensure quality and value for money and recommended that purchasers have sound monitoring arrangements in place and access to good comparative information about the quality and costs of HTHH services. It went further to recommend Lead Purchasing arrangements which in 1996-7 contracted with commercial organisations but from 1997-8 placed contracts with NHS tertiary centres.

The second was a report published in 1998 commissioned to explore the national response of purchasers to EL(95)5 [42]. It found that little priority had been given by Health Authorities to their responsibilities for purchasing HTHH which had led to inefficient contracting and poor value for money. Temporary arrangements established when implementing EL(95)5 [41] continue and purchasers express little willingness to review these mechanisms. Short and

Norwood [42] also recommended consortium or lead purchaser purchasing and highlight the lack of monitoring of contracts.

In the same year the proposed merger of Fresenius AG and Caremark Limited, both commercial providers of HTHH, led to a Monopolies and Mergers Commission Report [43]. This report collated detailed information on UK home care market and highlighted a lack of competition.

1.4 Background to this work

This project arose to evaluate a scheme which was set up, during the late 1980s and early 1990s, for patients to receive continuous ambulatory chemotherapy infusions at home. The scheme was very successful and it was hoped that the primary care team would get more involved with sharing the care of these patients with their secondary care colleagues to allow more patients access to this treatment. The original aim of this project was to evaluate home ambulatory infusions as a GP shared care initiative.

The publication of government directives on shared care [19], the managed entry of new drugs [21] and particularly the provision of HTHH [41] set a framework for the development of this project and the aims were adapted as follows:

SHARED CARE

AIM 1

To establish the current situation in England regarding the implementation of shared care arrangements under EL(91)127 [19] and subsequently under EL(94)72 [21] and to identify models which had been successful or otherwise.

AIM 2

To evaluate and critically analyze one example of an initiative intended to implement and facilitate shared care between primary and secondary care practitioners in South and West Devon.

HI-TECH HEALTH CARE AT HOME

AIM 3

To establish the current position in England on the purchasing and provision of HTHH under EL(95)5 [41].

AIM 4

To evaluate the effectiveness of EL(95)5 [41] in the delivery of HTHH to patients with an emphasis on the role of the pharmacist.

1.5 Development of a Benchmarking Tool for the Provision of Home Infusions

This work identified a severe inadequacy in both quality and outcomes monitoring of the provision of home infusion therapy in England. It was found that contracts are rarely put out to competitive tender, service specifications are rarely set and the outcomes of home infusion therapy are largely unknown by the purchasers of the care. Both purchasers and providers of home infusion therapy expressed concern regarding the lack of monitoring of quality. This was in contrast to the situation in the United States where home infusion providers must be accredited and benchmarking of the processes and outcomes of home infusion therapy has become normal practice.

Clinical audit has become a widely accepted tool for improving the quality of clinical care received by patients in the NHS but benchmarking has been demonstrated both in the manufacturing industry and more recently in service industries including health services to lead to greater improvements in outcomes. This is achieved by searching for and learning from best practice, which leads to superior outcomes, and adapting and implementing that practice to improve current performance. Benchmarking has been proven to produce improved patient outcomes in the home infusion industry in the United States [44-46] so this methodology was adopted in developing a tool to monitor quality and improve outcomes in the provision of home infusions in England.

The need for a benchmarking tool having been identified was addressed. The final aim of the project was therefore developed using this inductive approach.

BENCHMARKING

AIM 5

To develop a benchmarking tool for use by providers of home infusion therapy to monitor quality of care and improve patient outcomes (Chapter 4, Development of a Benchmarking Tool for the Provision of Home Infusions).

Chapter 5 draws conclusions and makes recommendations based on this work.

A review of the literature was carried out at the outset and forms the introduction to each chapter so that this work is put into the context of current knowledge and practice.

2 Shared Care

2.1 Literature Review

2.1.1 A Primary Care Led NHS

There has been much inefficiency in the NHS over the decades which have led in recent years to ever increasing costs of delivering health care and to a rethinking of the way the NHS functions.

The idea of creating an internal market within the NHS was first floated by Enthoven in his analysis of the NHS published in 1985 [1]. Two main pressures on the NHS were identified. Firstly, limited prospects for real growth in the level of resources. Secondly continued pressure to increase service levels due to demographic factors and increasing costs of new medical technology. The obvious solution, he suggested, would be to improve the effectiveness of the service within the available resources. Barriers to this included the fact that there was no incentive, other than job satisfaction, to deliver better quality of care at lower cost and that forces, particularly professional staff, made it difficult to bring about change within the NHS.

The Conservative government during the 1980's, took up the idea of a competitive internal market to give an incentive to increase activity, improve efficiency and quality, improve patient choice and to increase managers ability to manage the service by devolving decision making to a local level [1].

Three important white papers were published during the late eighties:

Promoting Better Health, 1987 [47]
Working for Patients, 1989 [48]
Caring for People, 1989 [49]

The main aim of 'Promoting Better Health' was to raise standards of health and healthcare, to place better emphasis on health promotion and disease prevention,

and to offer wider choice and information to patients. Many of these reforms were introduced through the contracts under which general practitioners provide services.

'Working for Patients' was the outcome of a ministerial review, established to address underlying problems in the management and funding of the NHS. Resource management programmes were implemented, general practitioners were provided with prescribing, analysis and cost (PACT) data to enable them to monitor prescribing patterns, medical audit was introduced across primary and secondary care and managers were expected to play a bigger part in the management of clinical activity. With contractual funding, responsibility for the funding and provision of services were separated. This put provider units under competitive pressure to improve quality and efficiency.

Local authorities were given the responsibility for the planning of community care in the white paper, 'Caring for People'. This was in an effort to overcome the uneven development of services across the country and was closely linked to new funding arrangements for residential care.

The 'NHS and Community Care Act', 1990, gave the government the legal power to implement the proposed changes and the internal market became a reality. General practitioner fundholding was introduced in 1991. Building upon the changes introduced by 'Working for Patients' came the idea of a primary-care led NHS whereby general practitioners either directly purchased or influenced the Health Authority purchasing through commissioning. The main aim of the proposals in 'Towards a primary care led NHS', 1994, was to ensure that decisions about purchasing were taken as close to the patient as possible [50].

Dinsdale [51] reported that fundholding general practitioners had begun to offer more services previously provided in hospitals but were slow to face the funding issues and bid for contracts so that the care of their patients could be brought nearer to their homes. He also reported guidance from the British Medical Association's General Medical Services Committee (GMSC) recommending that

general practitioners bill the health agency for individual items of service and suggests that Local Medical Committees (LMC) should agree the pricing of more common services in advance such as the monitoring of rheumatoid arthritis patients being treated with disease-modifying agents.

Brown, suggested [52] that reimbursements were probably the key to encouraging general practitioners to take on more secondary care patient services in the primary care sector. The secondary care directive, HSG[93]14 [53], allowed fundholding practices to become secondary care providers and make charges. It also allowed virements (where funding could be transferred from one fundholding budget category to another) and private contracts with providers, who were at that time the Family Health Service Authorities (FHSAs) and Health Commissioning Authorities (HCAs).

A primary care led NHS was becoming a reality and papers in management journals began to reflect this with articles on the need for Trusts to market their service to general practitioners [54] and others questioning the future need for district general hospitals [55].

Changing clinical behaviour in prescribing, referrals and other resource consumption allowed the release of resources which were subsequently spent on clearing waiting lists and improving community services [56]. This led to the potential problem of a two-tier system whereby patients of fundholders were treated quicker than those of non-fundholders. A study by the Organisation for Economic Co-operation and Development [56] concluded that fundholders were better purchasers than District Health Authorities (DHAs), were more willing to challenge hospital practices and to finally demand improvements. The best DHAs were however out performing their fundholders and the ethical question was raised whether it is appropriate to use fundholding to worsen the service. Addressing the question of whether a Labour government would change fundholding it was reported that Labour has been anxious to abolish fundholding but appeared to want to keep the benefits. It was concluded that the broad direction of a primary care led NHS was likely to continue with a Labour

government, with changes only in terminology and the detailed rules of fundholding.

By May 1996 there were about 50 total fundholding schemes underway. Purchasing consortiums were being formed by fundholders in a locality to become total fundholders but spread the financial risk [57]. Multifunds were also being created where a consortium of practices pooled their management allowance to enjoy economies of scale [58]. The National Association of Fundholding Practices was set up in 1992. Their view was that decisions made at grass-roots level are more likely to meet local need [59].

During the period of this research the Labour government came to power in May 1997. In December of the same year they released a White Paper [60] setting out a new structure and priorities for the NHS. As predicted fundholding was abolished, Primary Care Groups (PCGs) and later Primary Care Trusts (PCTs) were introduced. PCGs were formed from GPs in an area typically serving a population of around 100,000 people.

Within PCGs GPs were given responsibility for purchasing health services for their patients. They were given responsibility for controlling a single unified budget giving them choice on how to best meet the health needs of their local population. They were given freedom to make decisions about how they use their resources as long as they are consistent with an agreed Health Improvement Plan (HImP). The role of PCGs and PCTs is to work closely with Social Services Departments and City and District councils and to be accountable to the HA for commissioning health care. Four levels of Primary Care Group were introduced as a mechanism whereby they gradually took on more responsibility culminating in the Primary Care Group becoming a free standing body, a Primary Care Trust accountable to the HA for commissioning care and also having responsibility for providing community services. The first PCTs were formed in April 2000.

Health Authorities will still be responsible for strategic planning and prioritisation of health services. They will support GP commissioning groups

and have a new duty of partnership ensuring that they work closely with social services and local government [61].

Other developments introduced in the White Paper included:

- introduction of "NHS Direct" a 24 hour help-line for the public,
- speedier treatment for patients such as tighter targets on breast cancer referrals
- "NHSnet" linking all GP practices on the NHS's own information technology network,
- formation of the National Institute for Clinical Excellence (NICE) to promote clinical and cost effectiveness of NHS (A First Class Service: quality in the new NHS) [62].
- formation of the Commission for Health Improvement to ensure that clinical governance leads to high quality services being provided by all NHS organisations and to identify and disseminate best practice [62].
- The introduction of Personal Medical Services (PMS), Personal Dental Services and Local Pharmaceutical Services which are new types of contract with professional staff under independent contractors status.

The Green Paper, "Our Healthier Nation" [3] set targets to reduce deaths from heart disease and stroke, cancer and suicide and to cut the number of accidents. National Service Frameworks (NSFs) were introduced and will be developed and used as benchmarks to establish clear national standards for services to improve quality and reduce unacceptable variations in standards [62]. The first of these for Mental Health, Coronary Heart Disease and Care of Older People have been issued and National Service Frameworks on further subjects such as diabetes are expected.

In August 2000, the National Plan [5] was published with far ranging reforms across the NHS and targets for achieving them announced. A public consultation performed by the government in 2000 concluded that the public wanted to see

- a health service designed around the patient
- more and better paid staff using new ways of working
- reduced waiting times and high quality care centred on patients
- improvements in local hospitals and surgeries.

Whilst recognising that the NHS had been underfunded the government identified other problems

- a lack of national standards
- old-fashioned demarcations between staff and barriers between services
- a lack of clear incentives and levers to improve performance
- over-centralisation and disempowered patients.

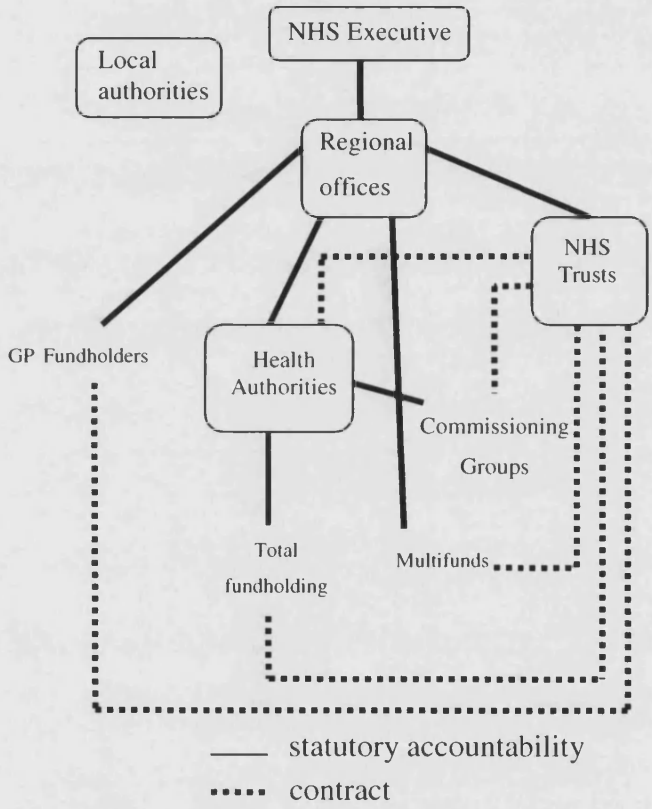
The Labour government states that the March 2000 Budget settlement will mean that the NHS will grow by one half in cash terms and by one third in real terms in five years. However, investment will be linked to reform. The Department of Health will set national standards, matched by regular inspection of all local health bodies by the Commission for Health Improvement. The National Institute for Clinical Excellence will ensure that access to cost effective drugs is equitable and a Modernisation Agency will be set up to spread best practice. Social services and the NHS will come together with new agreements to pool resources. There will be new Care Trusts to commission health and social care in a single organisation to help prevent patients - particularly old people - falling in the cracks between the two services or being left in hospital when they could be safely in their own home.

2.1.2 Organisation of the NHS

Changes in the funding of the NHS have led to the need for reviews of the structure of the organisation. On April 1st, 1996 100 Health Authorities became statutory bodies [63]. The Health Authorities Act, 1995 which allowed for this change legally repealed the NHS Reorganisation Act, 1973. The Regional Health Authorities were disbanded and instead one central and eight regional

offices of the NHS Executive (NHSE) were introduced. The NHSE was set up in 1991 and since then has played an increasingly prominent role in the operation and development of the NHS [64]. It is a part of the Department of Health and its staff are civil servants rather than employees of the NHS [63]. Its job is to develop NHS policy and be responsible for the management of the NHS [64] (Figure 2.1).

Figure 2.1 Structure of the NHS, April 1996- March 1999



Before April 1999 the NHSE managed the NHS directly through Health Authorities. HAs replaced separate DHAs and FHSAs and also the interim bodies that were created such as health commissions and health agencies. The HAs were responsible for planning for the health needs of their local population, and within that, for developing new patterns of service and effecting health improvements. They were expected to make sure that the public and patients understood and supported any changes necessary. This all had to be done within the budgetary allocation which was set by the NHSE from within the total amount agreed for health by Parliament. The amount allocated at parliamentary

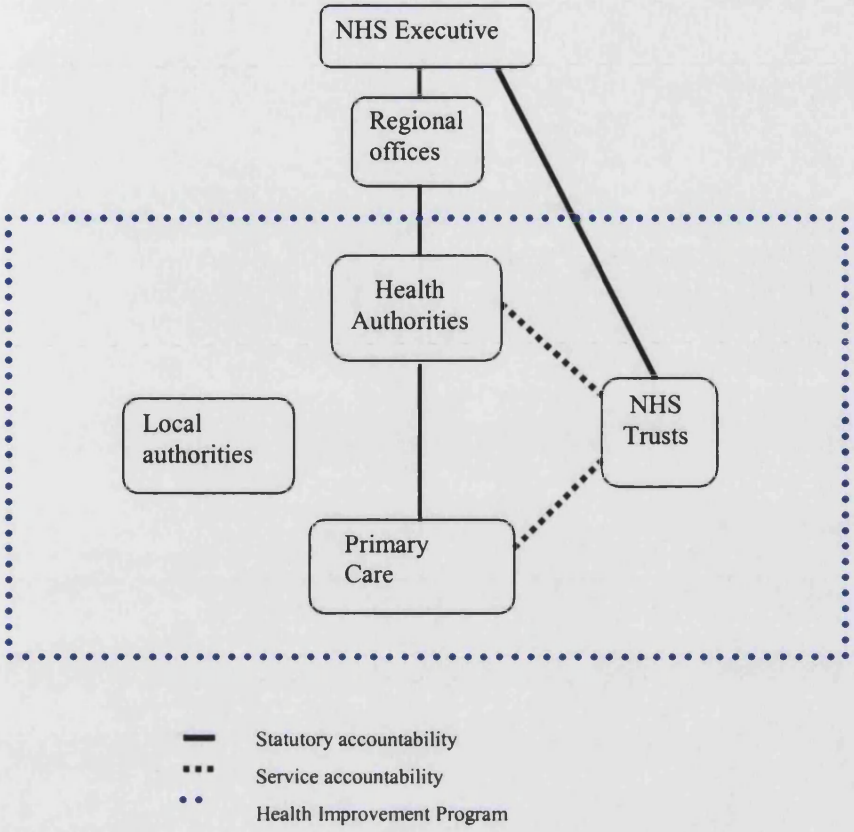
level was however, maintained within two separate budgets namely that for hospital and community heath services (HCHS) and that for primary care, including contractors. Money could not be transferred from one budget to the other [63].

Responsibilities of the Health Authorities (HAs) were outlined by the NHS Executive in a letter titled 'Managing Change' dated 28/7/94 and included implementation of NHS health policy, integrating purchasing across primary and secondary care boundaries and regulation and management of primary care services. The core functions of NHS taken on by the HAs were to evaluate the health and healthcare needs of the local population, establish and implement a local health strategy, and to monitor and evaluate change to ensure that strategic objectives were met.

With the introduction of PCGs, which happened after the collection of data for this project, it was again necessary to amend the structure and accountability of the NHS, the new structure as of April 1st 1999 is outlined in Figure 2.2.

Many of the roles of HAs are gradually being passed over to the PCGs and PCTs who will have statutory accountability to the HAs [65]. PCGs/PCTs are becoming responsible for allocating resources to meet the health needs of their local populations. They will be responsible for a unified health care budget and will take over commissioning from the HAs. The aim of this is to "align clinical and financial responsibility so that those who prescribe, treat and refer have control of the financial decisions they make" [4]. Avery [66] expressed concern that the government does not intend to support practices and their respective PCGs with the level of management allowances given to fundholding practices and with HAs becoming leaner bodies the government needs to be careful that it does not stifle attempts to improve primary care by failing to provide the funding needed to properly manage and support PCGs and PCTs.

Figure 2.2 Structure of the NHS, From April 1999 ([4]



The effect recent changes in the NHS might have on prescribing were discussed by Avery [66]. He predicts that with cash limited budgets GPs and PCGs will have to make difficult choices about rationing. However, unified budgets will allow greater pressure to be put on Trusts to take into account the cost of care such as drugs in the community when making their purchasing decisions. This may also be helpful in reducing the perception of cost shifting when care is shared between a Trust and a general practice.

As Dean [67] reported in 1996, GPs will have to be prepared to explain reasoning behind prescribing decisions to their patients. This could have a considerable effect on the special GP-patient relationship.

The data reported in this thesis were collected over the time period October 1996 to August 1999. The NHS structure pre April 1999 applied for most of the duration of this work. Regional HA boundaries were also changed on 1st April 1999. The data are reported in the regions, as they were when the information

was collected. The structure of the new NHS will be considered in the discussion of the work.

2.1.3 Shared Care

In November 1991, the NHSE produced guidance on the responsibility for prescribing at the hospital/general practitioner interface, in the form of EL(91)127 [19]. It reinforced the basic premise that the doctor who has clinical responsibility for the patient should prescribe and it focused on the concept of shared care, emphasising the need for proper hand over procedures from hospitals to make sure that the general practitioner was properly informed and could monitor treatment and adjust dose if necessary based on protocols for treatment.

Following this EL(94)72 [21] asked purchasers to develop a policy on the managed entry of new drugs making use of evidence of their clinical and cost effectiveness. They were instructed to develop and agree strategies for improving prescribing across the primary/secondary care interface and ensure appropriateness of hospital-led prescribing (taking into account total cost of drugs to the NHS). This made shared care initiatives part of the managed entry of new drugs and focused many shared care initiatives on the newer, often high cost and more complex therapies.

2.1.3.1 History of Shared Care in the NHS

The idea of sharing care between a hospital consultant and a general practitioner in the NHS is not a new one. It has proved a successful way of managing patients with conditions such as diabetes, hypertension, thyroid disease, rheumatoid arthritis and pregnancies for many years [14, 16, 18], although most arrangements have been on an informal basis.

2.1.3.2 Models of Shared Care

There have been a number of models of shared care. Shared care guidelines have been drawn up not only for shared care between GPs and hospital specialists but

also to outline respective responsibilities within a multidisciplinary team, either in primary care or in secondary care or across the interface [68-71]. Some shared care models in pregnancy [72] and HIV/AIDS [73], use a patient held record to facilitate communication between primary and secondary care, other models have involved the development of guidelines or protocols, flowcharts and computer programmes for managing a particular group of patients [17, 74].

Edwards *et al* [18] state that two models of GP responsibilities in shared care have emerged, "routine monitoring" or "investigation and treatment". They noted that the most common pattern of review was an annual review in hospital with three or four visits in general practice.

Evans [75] gives examples of three different models of shared care

- ***referral protocols*** specifying the investigations to be conducted before a patient is referred to a particular clinic
- ***prescribing protocols*** to smooth the shared care of patients on expensive drugs by stating whether the consultant or GP is responsible for the drug
- ***shared care protocols***, known as collaborative care plans written by a multidisciplinary team. They state agreed interventions for a given diagnosis, symptom or procedure within a certain time.

Another model of shared care is that where hospital consultants hold outpatients clinics in primary care settings. Black *et al* [76] studied outreach clinics and found that, although they reduced travelling distance and waiting times for patients, the expected improvement in communication only generally resulted from a chance meeting in a corridor rather than a structured communication method and even when clinics were held in the general practitioner's own surgeries communication was still by letter. Orton [14] reported the same problem, outreach clinics held in the early evening whilst GPs are having their surgeries do little to improve care, since they are simply outpatient clinics relocated, with no change in the primary/secondary care interface. However outpatient clinics held in the surgeries jointly with general practitioners or with

joint follow up and a meeting to discuss cases did improve communication. The main advantage was the potential for mutual professional education and the efficient use of primary and secondary care skills. Disadvantages included inappropriate use of resources, loss of close contact with other hospital departments, loss of immediate access to hospital facilities and a reduction in research and education activity.

2.1.3.3 Appropriateness of prescribing in secondary care/clinical responsibility

Evans [75] makes an important point that the debate on shared care protocols should not be whether they should be used but about their quality, as generally good guidelines are undoubtedly an asset to patient health care and poor ones a liability. The importance of clinician-led, practical protocols backed up by continuing education and audit of the effect of the guidelines was stressed with a suggestion that they could be updated by computer to ensure they do not get out-of–date.

2.1.3.4 Communication

Good communication and collaboration between health professionals in primary and secondary care have been a major key to success of these initiatives [77-79].

The lack of good communication is highlighted by Edwards *et al* [18] who report studies looking at communication between primary and secondary care. One shows that less than half of the questions asked by GPs on referral letters were answered by hospital consultants and another criticises most specialities for omitting information, although letters from psychiatrists were criticised for being too long and containing information the GP did not consider relevant.

2.1.3.5 Development of Guidelines

Experience of shared care in the Trent region has been reported by Wilson [77] (Symposium "Shared Care or Cost Dumping", 3rd March 1994). The guidelines that had been developed were mostly for newer, hi-tech drugs such as erythropoietin, intravenous nutrition and cyclosporin. The primary objective of

the shared care scheme was to improve patient's quality of life by allowing the patient to lead as normal a life as possible (in his or her own home rather than in hospital). The Trent Regional Drug Information service suggested that the realistic concerns that GPs have expressed about accepting responsibility for such patients could be overcome by a sensible, collaborative approach providing appropriate support, training and good communication [16]. They suggest that essential principles include GP agreement, giving GPs the opportunity to decline shared care arrangements without being put under pressure, involvement of general practitioners in drawing up the agreements, support and training for general practitioners, good communication channels between the relevant hospital consultant and general practitioner, not using the patient to communicate information and not using shared care as a means of shifting prescribing costs into general practice.

Edwards *et al* [18] recommend that the chair of a guideline development panel should not be an expert on the subject in question, there should be a full analysis of the literature, the guidelines should lead to the expected health or cost outcomes, they should be written from the perspective of general practice and should be comprehensive and flexible in approach. Local ownership of the guidelines is widely considered important to their success.

Martin [80], a hospital pharmacist with responsibility for drawing up shared care guidelines in Leeds for the managed entry of new drugs under EL(94)72 [21], advises that to maintain a good relationship between primary and secondary care sectors, GPs must only prescribe drugs when it is appropriate clinically and financially for them to do so. The Pan Leeds Prescribing Committee with representatives of the HA, three Trusts and local GPs ultimately approve the guidelines developed in Leeds.

The need to formalise shared care through guidelines is discussed by Joshua [81]. She states that an important component of shared care is the cost shifting element whereby GPs agreed to be responsible for the financial burden of treatment which might not otherwise be available to the patients because of the cash limits imposed on hospitals. For shared care to be truly effective she argues that GPs

must have a real clinical involvement in patient management and must be able to accept shared care patients without prejudice to their indicative prescribing amounts, prescribing targets or future funding. If this was not the case GPs would interpret shared care as merely a cost-shifting exercise which would cause resentment.

A study carried out in the North West region in 1996 [82] asked hospital pharmacy departments whether they had requested that GPs prescribe any of a list of eight treatments not normally used at the time within general practice and if so whether they had any shared care protocols for these drugs. 95% had asked GPs to prescribe at least one of the drugs. 69% had no written shared care protocols for any of the eight treatments listed. Half of the hospitals which asked GPs to prescribe Continuous Ambulatory Peritoneal Dialysis fluids, fertility treatments, cytotoxics and proton pump inhibitors had no written protocols for these treatments in operation or under development. Shared care protocols available included those for dornase alpha, goserelin, interferon, cyclosporin, diabetes, asthma and gastrointestinal disease.

Fellows [20] claims that many hospital consultants do not understand the legal issues of prescribing and the fact that when a GP signs a prescription this confers legal responsibility to him or her. He states that concern about costs blurs the professional issues and uncomfortable feelings of cost dumping are not misplaced. PCGs with unified budgets he predicts will solve some of these cost considerations but the clinical and legal responsibility, workload shift and patient convenience problems will remain. He makes the point that GPs have the right to refuse to prescribe when they do not feel competent to do so but that GPs are often in a difficult position when their patients are in rural areas and would have difficulty collecting prescriptions from the hospital. He suggests a change in the law so that a GP could prescribe as a consultant's deputy in situations where they are not happy to accept the full responsibilities of shared care. He feels a payment for this would be in order so that it would not be used to dump workload. Another alternative would be to develop a new form of consultant prescription which could be authorised for repeat dispensing from a community pharmacy.

Dean [67] discussed the prescribing dilemma that general practitioners will be increasingly facing with the introduction of more expensive drugs, such as interferon β for multiple sclerosis. He suggested that, whilst it was not currently the case that the cost of parenteral home therapy be borne by general practice, it would no doubt be an issue for the future and the drugs used, such as expensive antibiotics like teicoplanin, may well have a significant impact on their prescribing budget and rational prescribing decisions about therapies would have to be made.

2.1.3.6 Evidence of the Effectiveness of Shared Care

2.1.3.6.1 Studies

There have been many reports of shared care arrangements but very few well-designed studies demonstrating evidence for the success or otherwise of various models of shared care.

The use of computers to assist shared care in hypertension was reported by Petrie *et al* [78] in 1985. A shared care scheme for the long-term follow-up and management of hypertensives was set up in the Grampian region of Scotland. The study looked at what is still today the most important tool for shared care, the exchange of information between doctors in the primary and secondary care settings. The principal effects of introducing shared care were a reduction in the number of patients under regular long-term follow-up at the hypertension clinic, a reduction in hospital clinics, an intensification of the attention paid to the highest risk patients, and a reduction in patient contacts with inexperienced hospital staff.

A similar project was reported, again in Scotland, in 1994 [17]. Patients were randomly allocated to shared care or outpatient clinic follow-up. After two years 82% of shared care patients had had a complete review, compared with 54% of outpatient clinic attendees and 75% of nurse practitioner clinic attendees. Blood pressure control was similar in each group. 61% of questionnaire respondents

subsequently wanted shared care to continue 25% were unsure. The rank order of cost effectiveness ratios was shared care, nurse practitioner care and conventional outpatient care. It was concluded that shared care for hypertension was feasible, acceptable to the majority of participants and was a cost-effective method for long-term follow up.

Griffin [83] performed a meta-analysis of randomised controlled trials of diabetes care in general practice. He found that in shared care schemes featuring more intensive support, through a computerised prompting system for GPs and patients, there was no difference in mortality between care in hospital and care in general practice. Glycolated haemoglobin tended to be lower and losses to follow-up were significantly lower, in primary care. However, schemes with less well-developed support for family doctors were associated with adverse outcomes for patients. The value of this meta-analysis being extrapolated to primary care outside of clinical trials was questioned by Greenhalgh [84].

The GRASSIC project [85] used a computer-based patient records scheme in the shared care of asthma patients, where patients were reviewed by a chest physician annually and by their GP, three or four times a year. The reduction in the amount of specialist contact was not associated with worse asthma management, patients benefited financially and they were at no clinical, psychological or social disadvantage than patients treated under the traditional model of outpatient care.

Kirby *at al* [74, 86] [87] developed a shared care flow diagram for the shared care of benign prostatic hyperplasia (BPH) between urologists and GPs. A questionnaire survey of 2020 urologists, general practitioners and other interested clinicians achieving a 28.7% response rate revealed that there was consensus among respondents that a shared care approach to the management of benign prostatic hyperplasia may improve the standard of care provided by GPs and allow urologists to focus greater attention on those patients who require their surgical expertise.

Rapporteurs at a joint conference of the Royal Colleges of Physicians and General Practitioners on shared care in HIV and AIDS [88], reported Shaunak's description of a model of shared care set up "before the complexities of combination therapy". A locally relevant management guide was constructed and a one-page standard summary of patient attendances and admissions and information relevant to primary care was faxed to the GP. The GP had 24-hour access to an HIV consultant. The project reduced the number of outpatient visits, halved the average duration of inpatient admissions, increased GP consultations and reduced costs to specialist units. The motivation and determination of the facilitator in encouraging GPs, specialists and patients was vital to the success of this project. This specialist HIV unit was subsequently closed, due in part to the reduction in activity as a result of the success of the shared care model.

The benefits of shared care have however been called into question. Sowden *et al* [89] queried the national adoption of shared care schemes. They report an extensive literature review on the shared care of diabetes patients. In none of the randomised trials did shared care improve clinical outcomes, compared with hospital care and in two of the studies it was associated with poorer care or outcomes. They called for further research and some definition of the key features of a shared care programme, as those aspects of shared care that might be important in influencing process and outcome may otherwise remain unclear. It is also noted that most studies involve volunteer practices who may well be more motivated and achieve better results. The authors conclude that the effectiveness and cost-effectiveness of shared care remain uncertain and that trials that take into account the complexities and interactions of setting, provider interest, and consumer preference are needed.

McGhee and Hedley [90] disagree with this and give examples of studies in diabetes and hypertension where shared care was associated with lower drop out rates and was more cost effective for the patients. They also point out studies in hypertension and thyroid disease that have shown cost effectiveness for the health service and a reduction in the number of patient-clinician contacts while the standard of review was maintained. They suggest that further research

should be directed at identifying the best approaches to shared care rather than comparison with traditional methods.

Tucker *et al* [72] showed that care given by a midwife and GP is at least as effective for the routine antenatal care of low risk patients as shared care with a hospital consultant and in fact those cared for by the primary care team had lower incidences of pregnancy-induced hypertension, proteinuria and pre-eclampsia.

2.1.3.6.2 Case studies

Most publications that have extolled the virtues of shared care have been based upon anecdotal evidence. A number of centres have reported their experience of the pros and cons of shared care arrangements. The issues of clinical responsibility, appropriateness of prescribing some complex therapies in primary care, cost shifting and workload shifting are common themes [15, 16, 20, 67, 88, 91].

Shared care initiatives in managing patients with HIV and AIDS have been widely discussed [73, 88, 92, 93]. Williams [93] in a letter to the British Medical Journal called for more primary care involvement in the treatment of AIDS patients for the patients' benefit. It was reported that many general practitioners use the high cost of the drugs involved as a reason for not being involved with the care of these patients but the author believed that expensive drugs should be funded centrally regardless of whether the patient is managed in primary or secondary care. Grun and Murray [73] contributing to a debate about the funding of the treatment of these patients described a trial of a shared care protocol that had been in place for the treatment of HIV and AIDS patients. The patient held a card with a summary of relevant medical history and current drug therapy and a chart for completion at each consultation. After baseline investigations were completed at the hospital clinic, the general practitioner saw the patient at three monthly intervals and the patient was reviewed at the hospital annually. Advantages of the scheme included the chance to build-up a good doctor-patient relationship early on whilst the patient was still well and relieving pressure for hospital appointments.

Sharing the care of patients with infertility problems has caused much debate as it has often been the high cost of the drugs involved which has been the factor which has prompted the request from secondary care for the general practitioner to prescribe the drugs. Most GPs try to treat the more obvious causes of infertility such as obesity and thyroid function themselves but refer to secondary care when more complex investigation is warranted. Hospital pharmacy budgets often preclude hospital practitioners from prescribing more than one or two weeks supply of infertility drugs and this has thrown the burden of prescribing into the community [94]. Equally some Health Authorities exclude *in-vitro* fertilisation from their contracts with NHS Trusts and this has led to a variety of private practice with requests to prescribe coming from the private sector. With more intensive forms of ovulation induction therapy adequate monitoring and experience of managing complications is necessary but not usually available in primary care where the drugs are prescribed. Taylor and Braude [94] recommended that general practitioners should ask for written assurance from the unit treating the patient that they will monitor the cycle appropriately and take responsibility for, and care of, any complications that may arise as a result of this type of therapy. Private specialists have been known to put general practitioners in a difficult position by sending patients to their general practitioner for prescriptions of gonadotrophins and gonadotrophin releasing hormone analogues.

Patients with prostate cancer are another group in whom shared care has been advocated. Gingell [95] described how, once the patient has been stabilised on maintenance treatment by the specialist the general practitioner can take over responsibility. The patient must be seen regularly to assess performance status and analgesic requirements and to encourage compliance with oral medications. Side effects can be monitored and where necessary treatment modified. Monitoring of the patient using appropriate blood tests, weight and blood pressure can be performed by the general practitioner. Patients can benefit from the timely intervention of radiotherapy to painful metastases, blood transfusion and good pain control if good communication and co-operation are achieved between the professionals in primary and secondary care.

The involvement of general practitioners in clozapine therapy for schizophrenic patients was described by Launer [96]. Even though general practitioners could not prescribe this drug, it was reported that they helped to identify patients suitable for treatment with a poor quality of life. They should be aware of the potential drug interactions and adverse effects of clozapine. They can also provide support for families who may have difficulty coming to terms with their 'awakened' sons and daughters. The issue of shared care in long term mental illness was discussed by Wright [79] in an editorial. General practitioners have reported an increase in workload resulting from patients being discharged from mental health hospitals due for closure. He reports a follow up study of schizophrenic patients one year after discharge into the community which revealed considerable use of general practitioners but little use of community facilities.

Twin conferences were held, in 1994, in London and Llandridnod Wells, sponsored jointly by the Royal College of General Practitioners and the Royal College of Psychiatrists called 'Making shared care work' [79]. The need for multidisciplinary training and reliable information was highlighted. A lack of provision of information to patients and their carers have been identified as problems that need to be overcome by both the primary and secondary care teams.

Pinn [97] reported that services for epileptic patients could be improved through local agreements between general practitioners and specialists. He points out the relatively high incidence of epilepsy and the low numbers of neurologists, particularly those professing to have a specific interest in epilepsy. New and better drugs are becoming available but expertise is required to use them sensibly and efficiently. He reports a survey of 200 consultant neurologists which highlighted very low usage of formalised shared care arrangements between general practitioners and hospital specialists and points out that in the meantime general practitioners are left to deal with the day-to-day management of patients with epilepsy without any clear cut idea of where their responsibilities begin and end.

2.1.3.7 Shared Care of Hi-tech Health Care at Home

Hi-tech Health Care at Home (HTHH), as defined by EL(95)5 [41] was one of the more common subjects of shared care guidelines developed through the early 1990s [77].

Nelson [98] reported experience of the shared care of children with cystic fibrosis, receiving intravenous antibiotics at home. Most of the patients preferred to be treated at home and thought that they were given adequate support for home treatment. A questionnaire revealed that patients thought that their general practitioner should be more involved. Parental anxiety was a problem as there was concern that other medical problems would not be recognised. Drugs and treatment were delivered in one of three ways, the cheapest being directly from the hospital. General practitioner prescriptions from the local pharmacy were expensive and no more convenient than the hospital. Unicare, a commercial organisation was a cheaper alternative and allowed delivery direct to the patients' homes.

Orton [14] notes that shared care must also be flexible and carried out in the home setting where patients are increasingly being treated with more complex problems. In the United Kingdom he says the key question as to whether general practitioners are willing to extend their role to inpatient care has not been answered. Shared care he concludes offers the opportunity to alter the balance between primary and secondary care and to question whether secondary care is always needed. It will be facilitated by new technologies that provide support for practice decisions and enhance the exchange of information.

Bryan [15] reported that general practitioners were invariably happy to prescribe insulin or an ACE-inhibitor when asked to by a hospital consultant but when a suggestion was made of sharing the care of a myeloma patient with the local oncologist and prescribing alpha-interferon, for example, neither the general practitioner or FHSA had been quite so keen. She reports that attempts by the NHS Executive going back to 1991 had failed to convince general practitioners

and FHSAs that indicative prescribing and fundholding schemes should not deter them from taking part in shared care arrangements. She suggests that EL(95)5 [41] may, at last, make the most expensive shared care arrangements 'flavour of the month on both sides of the primary/secondary care divide'. Shared care schemes set up successfully at the Christie Hospital in Manchester were described. The importance of consultation with all parties in drawing up guidelines was stressed. Around 50 cancer patients at any one time were signed up for shared care arrangements. They were mostly receiving alpha-interferon, 5-FU or octreotide, but only 5-FU was covered under the arrangements outlined in EL(95)5 [41]. In South Thames the EL had been pre-empted and a system was in place where drugs were categorised into red and amber groups. Red meaning general practitioners should not prescribe. This list contained most drugs covered by EL(95)5 [41] and amber meaning they may choose to. Initially all new drugs went on the red list but could be transferred to amber as experience with them was gained. In Manchester a survey showed that more than 50% of patients liked the system, mainly because visiting the general practitioner was much more convenient than the hospital. However a study in Birmingham [15] had found that patients were dropping out of an interferon shared care protocol because they were having difficulty giving themselves injections.

General practitioner involvement in sharing the care of patients being treated at home with intravenous antibiotics was advocated by Conlon [99]. He notes that some general practitioners may view home intravenous antibiotic therapy as yet another attempt by hospitals to transfer the clinical workload to the community. Others, however may be excited by the prospect of being able to diagnose a soft tissue infection requiring intravenous antibiotics, arrange for an intravenous line to be inserted and then manage most of the therapy at home, referring to the hospital team only for specific problems. He comments that it is possible to run a home intravenous programme, with community nurses administering the antibiotics, without general practitioners taking on any of the work themselves. It is also possible for general practitioners to become actively involved and even to operate a small intravenous team from a health centre.

A study in East Anglia [100] found that prevalence of home artificial nutrition had doubled form 1988 to 1993 but overall standards of care were not keeping pace. They found that GPs were confused about the legislation and their clinical responsibility for these patients treated with home TPN and enteral nutrition. In a recent article Pennington [101] describes the importance of the primary health care team in the support and management of home TPN patients in dealing with this demanding and disrupting treatment.

With almost any chronic condition or drug therapy, shared care has been practiced or studied. Pharmaceutical companies are even sponsoring and distributing shared care guidelines for their drug, such as Britannia Pharmaceuticals Limited with apomorphine for Parkinson's Disease and Novartis Pharmaceuticals UK with letrozole in breast cancer. These guidelines should be looked upon with caution as in studies undertaken so far, a factor in the success of shared care guidelines has been local development and agreement by those who will be using them [16, 18].

2.2 Shared Care Surveys

2.2.1 Project Aims

- To establish the current situation in England regarding the implementation of shared care arrangements under EL(91)127 [19] and subsequently under EL(94)72 [21] and to identify models which had been successful or otherwise.
- To evaluate and critically analyse one example of an initiative intended to implement and facilitate shared care between primary and secondary care practitioners in South and West Devon.

2.2.2 Objectives

Questionnaire survey of the 100 Health Authorities in England to establish:

- if shared care guidelines have been developed and implemented and if so for which drugs/conditions
- who has been responsible for the development and implementation of shared care guidelines?
- which aspects of shared care have been successful/unsuccessful?

Questionnaire survey of General Practitioners (GPs) working in the area covered by South and West Devon Health Authority to:

- find out the opinions of local GPs on the concept of "shared care"
- establish if the local procedure for the development of guidelines is successful
- establish whether the guidelines being produced locally fulfil GP expectations

2.2.3 Background On The Local Shared Care Situation In South And West Devon

2.2.3.1 Formation of the South and West Devon, Cornwall and Isles of Scilly Shared Care Working Group.

Within South and West Devon there are three main secondary care providers, Plymouth Hospitals NHS Trust and Plymouth Community Services NHS Trust covering Plymouth and the surrounding area and South West Devon Health Care NHS Trust covering the Torbay area . Plymouth Hospitals NHS Trust is also the main secondary provider for a large part of Cornwall and has substantial contracts with Cornwall and the Isles of Scilly Health Authority. It was felt that for shared care to work meaningfully a joint approach between the two Health Authorities was required and therefore, in response to both EL(91)127 [19] and EL(94)72 [21], the South and West Devon, Cornwall and Isles of Scilly Shared Care Working Group (SCWG) was formed. The SCWG drew representatives from Health Authorities, the local acute Trusts, primary care and the relevant Local Medical Committees. Terms of reference were drawn up and a quorum established.

Key points of the terms of reference of the SCWG are shown below:-

a) to achieve clinical consensus on shared care guidelines which will be clinically appropriate and acceptable for GPs and consultants in South and West Devon and Cornwall and the Isles of Scilly.
b) to consider those drugs where there is a common view between clinicians (and Health Authorities) that the drugs are suitable for shared care arrangements.

The focus of the group was on clinical rather than financial issues and the appointment of a GP chairperson helped reinforce this message. The main role of the Health Authority was one of facilitation and providing a secretariat to service the work of the group.

2.2.3.2 Guideline Development

It was soon found that clinical consensus was not easy to obtain, especially where one consultant took the lead on drawing up a guideline, so a procedure was adopted whereby a Health Authority pharmacist drew up draft guidelines from readily accessible and respected reference sources such as the British National Formulary, Martindale, Association of the British Pharmaceutical Industry Data Sheets, Summaries of Product Characteristics and consensus statements from the Royal Colleges. A standard template was adopted which covered the areas of guidance specified in EL(91)127 [19] together with information on adverse drug reactions, drug interactions and some basic background pharmacology.

After initial discussion by the multidisciplinary SCWG consultation with hospital specialists was undertaken. Areas of difference were resolved by adherence to some key principles:

a) Conformance with product licence/data sheet
b) The presence of a body of evidence to support a view.
c) Identification of minor differences in local practice which did not substantially alter the management of a patient under the guideline.

2.2.3.3 The Working Agenda

It was felt important to respond to locally perceived need and priorities. Referral to the SCWG from Health Authority prescribing committees generated the early working agenda, which led to development of guidelines for erythropoietin, riluzole, dornase alpha and cyclosporin. As part of the Health Authority's programme to manage the entry of new drugs, policy statements on new drugs included information on whether the drug was considered appropriate for shared care and if it was the SCWG was asked to add the drug to it's work plan. Concerns of GPs raised with Health Authority Pharmaceutical and Medical Advisers also led to the tabling of drugs where shared care guidelines would be helpful such as for lithium prescribing. The work of this project elicited opinions of GPs on which drugs/diseases they would like shared care guidelines for

(2.2.5.2.5) and this information was fed back to the SCWG for development of the work plan.

2.2.3.4 Guideline Dissemination

The two Health Authorities took different approaches to dissemination of the shared care guidelines, South and West Devon funded ring binders for each GP with an updated cumulative index when new guidelines were distributed. Cornwall and the Isles of Scilly Health Authority adopted an "available on request" approach.

2.2.4 Methods

All questionnaires used in this research were developed in the same way. The questionnaire that went to Health Authority Medical/Pharmaceutical Advisers covered both shared care and HTHH. To avoid repetition the methodology for all questionnaires will be described in this chapter and differences noted in the relevant chapters.

2.2.4.1 Literature Review

A detailed, fully referenced literature review was prepared (2.1). The reference database was stored on a computerised library system using Endnote® software. NHS Management journals were scanned for relevant articles and used as a basis for collecting other recent articles and discussion papers. Previous work of this institution was collected and the Director of Pharmacy of the Trust and the Pharmaceutical Adviser of the local Health Authority were asked for any information that they had been sent or had collected on the issues of shared care or HTHH. Colleagues known to have an interest in HTHH were contacted to discuss the various models of provision of HTHH currently in use. The literature review was used as a basis for further work.

2.2.4.2 Health Authority Survey -Response To EL(91)127 And EL(94)72

The initial aim of the project was to establish the current level of development of shared care initiatives in England. Both EL(91)127 [19] and EL(94)72 [21] gave Health Authorities responsibility for developing strategies to break down barriers between primary and secondary care by facilitating the introduction of shared care arrangements for prescribing at the hospital/general practitioner interface. For this reason a survey of Health Authorities was used for determining the progress made on shared care throughout the country.

2.2.4.3 General Practitioner Survey

The second aim was to evaluate and critically analyse the shared care arrangements implemented locally in South and West Devon. General practitioners are central to the concept of shared care and it was considered important to seek their views on both current and future arrangements for sharing the care of patients with their secondary care colleagues.

2.2.4.4 Development Of The Questionnaires

2.2.4.4.1 Questionnaire Design

Questionnaire design techniques were researched from textbooks and courses before the questionnaires were developed [102-105] (Questionnaire Design Course, Research Support and Development Unit, Plymouth Hospitals NHS Trust). All questionnaires were sent out with a stamped addressed envelope for return of the questionnaire and a covering letter explaining the aims of the project, who was funding it and what the data would be used for (Appendices 1 and 2).

2.2.4.4.1.1 Development Of The Health Authority Questionnaire

It was known that Pharmaceutical and Medical Advisers of Health Authorities commonly represent the Health Authority on committees discussing shared care arrangements. It was therefore decided to aim the questionnaire at Pharmaceutical Advisers or Medical Advisers of Health Authorities.

The NHS Executive was approached for a current list of Health Authorities in England. They provided the eight regional directories for 1997/98 listing all the Health Authorities, Trusts and Community Health Councils in each region with addresses and telephone numbers. Other sources of information were explored but this was considered to be the most up-to-date.

A questionnaire was drafted, based upon the aims and objectives of the project listed in Sections 2.2.1 and 2.2.2. The draft questionnaire was sent to the local Pharmaceutical Adviser, the local Research and Development Support Unit (RDSU) and the supervisors of this project for comment. Based on their comments the questionnaire was adapted and the second draft was again sent out for comments. Using these comments a pilot questionnaire (Appendix 1) was drawn up and was distributed at a regional meeting of Pharmaceutical Advisers for the South and West region. 11 questionnaires were distributed with a letter (Appendix 1) asking for the recipient's comments on the content and design of the questionnaire and what, in their opinion, was the best way to distribute the questionnaire.

After six weeks a telephone call was made to each of the remaining recipients to prompt a response to the questionnaires and a letter sent to any Pharmaceutical Adviser who could not be contacted by telephone. After a further four weeks a further telephone call was made and a further questionnaire sent.

A database was set up (using Microsoft Access® software) to keep a record of the recipients of the questionnaire and details of telephone and written reminders.

The design of the final questionnaire (Appendix 2) was based upon the comments received from the pilot. It was made shorter and less detailed information was requested. The major comment from the pilot was that the questionnaire was too long. The questions regarding shared care committees were changed to ask which committee was responsible for agreeing shared care guidelines and the layout of the questionnaire was improved. The length of time

taken in the pilot to complete the questionnaire was used as a guide on the final questionnaire.

Results from the pilot and comments from the respondents suggested that a good response rate would not be achieved if the questionnaires were merely distributed by mail. Taking advice from the pilot and from Regional Pharmaceutical Advisers to the NHS Executive and with their help the researcher elected to try to visit the eight regional meetings of Pharmaceutical and/or Medical Advisers in England. The aim was to personally distribute the questionnaire (Appendix 2) at the same time as explaining the aims of the importance of receiving information from all Health Authorities.

As completion of the questionnaire required considerable input from the respondents to obtain the information required, and as changes as a result of the pilot were minor, requiring in most cases less detailed answers, the pilot questionnaires from the South and West Region were used in the final data analysis.

Between May and November 1997 the researcher was able to attend six regional meetings, some of solely Pharmaceutical Advisers and some joint meetings with Medical Advisers. The questionnaires were distributed at the meetings with an explanation of the aims and objectives of the project either from the researcher, or where the meeting was not attended, from the Regional Pharmaceutical Adviser.

During visits to the regions other unpublished projects and reports that had been commissioned came to light [6, 42, 106] and these together with comments that came from the discussions with the Pharmaceutical and Medical Advisers were taken into consideration when formulating future questionnaires.

2.2.4.4.1.2 Development Of The General Practitioner Questionnaire

Due to the very large number of GPs in England, a sample population was chosen for the purpose of the survey. For ease of distribution and because the

local Health Authority were interested in the attitudes of local GPs to the procedure for agreeing and implementing shared care guidelines in South and West Devon, the questionnaire survey targeted all GPs working in the area defined by the South and West Devon Health Authority geographical boundaries.

A draft questionnaire was drawn up and distributed to the Chair of the Local Shared Care Committee, the Health Authority Pharmaceutical Adviser, Trust Director of Pharmacy and supervisors of this project for initial comments. Based on this, the pilot questionnaire was prepared (Appendix 3). Six GPs were asked for comments on the design of the questionnaire and responses were received back from five. These comments were used to develop a final questionnaire (Appendix 4).

The paragraph explaining EL(91)127 was felt to be difficult to follow so the main points were pulled out into bullet points both for the letter and the front cover of the final questionnaire. Suggestions were made about the order of the tick box responses in Section 1, question 2 by two GPs. In Section 1, question 3 the word "generally" was moved to cover all answers and a further response was added "prescribe it providing it is not too expensive". In Section1, Question 5 it was suggested that it would be helpful to include some examples. In Section 2 Question 1 the wording of the first bullet point and the last two bullet points was changed to make the question clearer.

The objectives of the survey are listed in Section 2.2.2.

The final questionnaire was sent out via the Health Authority courier and names and addresses were obtained from the HA database. 357 questionnaires were sent.

2.2.4.4.2 Interpreting The Results/Coding The Data

A Microsoft Access® database was set up for each questionnaire with a form for entry of data that resembled as closely as possible the questionnaire from which the data was being entered to ensure accurate data entry. Codes were developed to allow faster data entry for the simplest questions. In the case of open

questions where respondents were asked to comment, the prose was entered onto the database. An independent person (a Senior Pharmacy Technician) checked all of the data entered for accuracy.

2.2.4.4.3 Health Authority Questionnaire

The respondents of the Health Authority questionnaire were asked six open questions regarding aspects of shared care that had been successful or difficult/problematic. Common concepts and themes in the data were identified and developed in order to classify the data into a coding frame.

In order that the coding of this data be validated three groups were asked independently to code the data. An inductive approach was taken whereby the coding frame(s) were developed after the data collection exercise by the various groups asked to code the data. This method was employed so that the depth and quality of the data collected was not lost. The researcher facilitated the meeting but had no input into discussions regarding the data. The meetings were recorded on audiotape in order that the reasoning of the groups in coming to their decisions could later be compared.

The three groups asked to code the qualitative data were

I. 3 hospital pharmacists

II. 4 members of the Health Authority Team (including one GP who chairs the local Shared Care Committee, one member of the contracts department and two members of the prescribing team, one of which was a pharmacist)

III. 3 members of the Trust finance staff

The raw data is shown in Appendix 5. The groups were given data in this format to code and the original questionnaires were available for them to refer to for clarification.

2.2.4.4.4 GP Questionnaire

Qualitative data obtained from the survey of GPs was analysed by a group of two GPs and a Health Authority Pharmaceutical Adviser. One GP from the Torbay area and one from the Plymouth area were chosen as these areas are covered by different secondary care providers. Similar methodology was used to that described in Section 2.2.4.4.2.

The results of the survey were fed back to the South and West Devon, Cornwall and the Isles of Scilly Shared Care Working Group, a summary of findings was sent to anyone who requested one on the questionnaire and the findings were presented orally at the National Prescribing Centre Conference for Health Authority Advisers, 18th-19th June 1998, Hinckley, Leicestershire.

2.2.5 Results

2.2.5.1 Health Authority Questionnaire

2.2.5.1.1 Response Rate

Questionnaires were distributed to each of the 100 Health Authorities in England via the Pharmaceutical or Medical Adviser. 87 responses were received. The number received from each of the eight regions is shown in Table 2.1.

Table 2.1, Number of Responses by Region, Health Authority Questionnaire

region	No. of replies	No. of HAs	No of non-responders
Anglia and Oxford	8	9	1
North and Yorkshire	12	13	1
North Thames	10	14	4
North West	14	16	2
South and West	12	12	0
South Thames	11	12	1
Trent	9	11	2
West Midlands	11	13	2
TOTAL	**87**	**100**	**13**

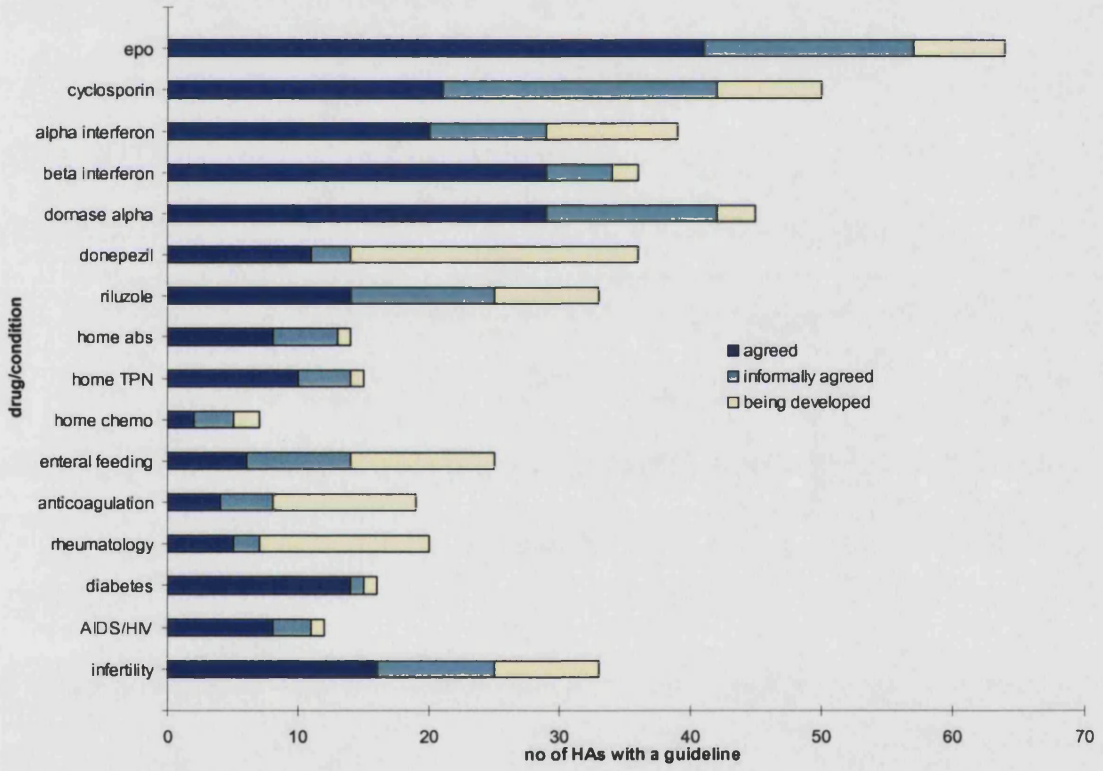
75 were completed by a Pharmaceutical Adviser, 4 by a Medical Adviser, 3 jointly by a Pharmaceutical Adviser and Contracts Manager and one entirely by a Senior Contracts Manager, the other 4 were completed jointly with the help of a Consultant in Public Health, Medical Adviser, Directors of Pharmacy of Trusts and a Commissioning Support Manager, respectively.

2.2.5.1.2 Current Guidelines

81 of the 87 (93.1%) respondents had some kind of shared care guidelines for sharing the care of patients between primary and secondary care in their area. This included three Health Authorities (HAs) who had generic guidance but most had disease or drug specific guidelines. There were five HAs, all in one region, who said that guidelines were regionally produced and 3 other HAs who were using shared care guidelines as part of a virement project from primary to secondary care.

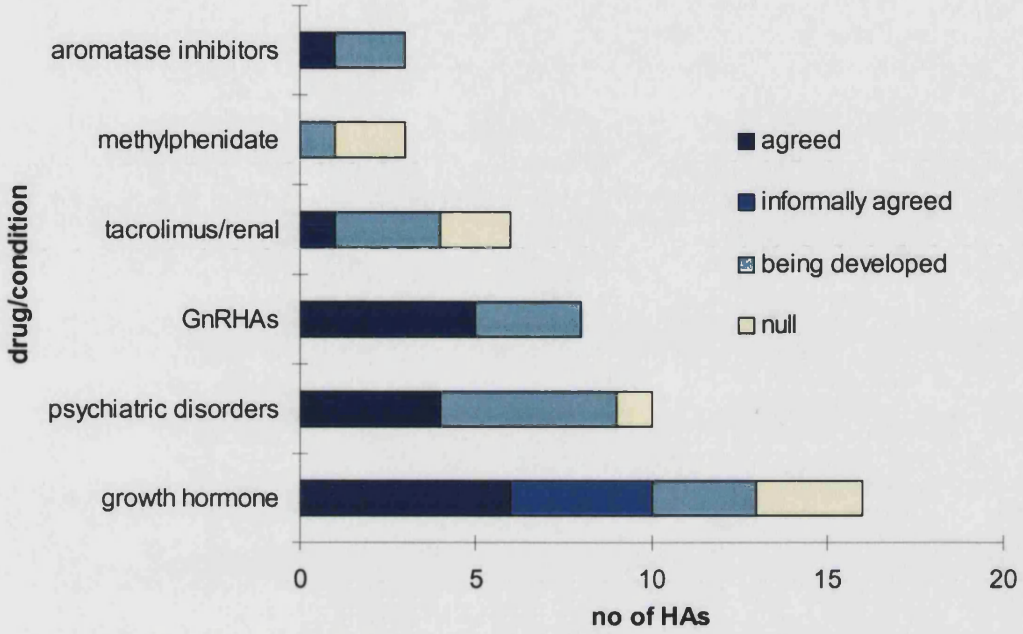
Figure 2.3 shows the number of HAs with a guideline for the drugs/conditions specified on the questionnaire. Erythropoietin was the most common subject of the shared care guidelines, where 65/87 HAs (56%) had a guideline that was either "formally agreed" (41), "informally agreed" (17) or "being developed" (7). The least common subject of a shared care guideline was home chemotherapy with only 7/87 (8%) HAs having any sort of shared care guideline, (2 "agreed", 3 "informally agreed" and 2 "being developed").

Figure 2.3, Number of Health Authorities with Shared Care Guidelines for Various Drugs/Conditions (n=87)



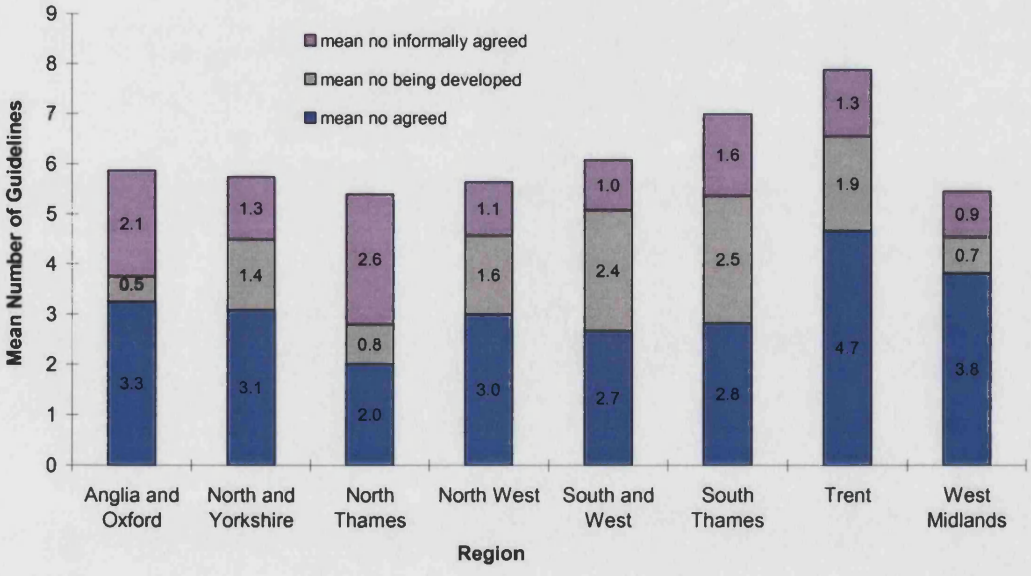
Other shared care guidelines being used are shown in Figure 2.4. They include growth hormone (16 HAs), psychiatric disorders (10 HAs), Gonadotrophin Releasing Hormone Analogues (8 HAs).

Figure 2.4, Health Authority Questionnaire – Other Shared Care Guidelines That Have Been Developed Locally (n=87)



The mean number of guidelines per Health Authority was six. Figure 2.5 shows the mean number of guidelines per Health Authority by region. There was little regional variation.

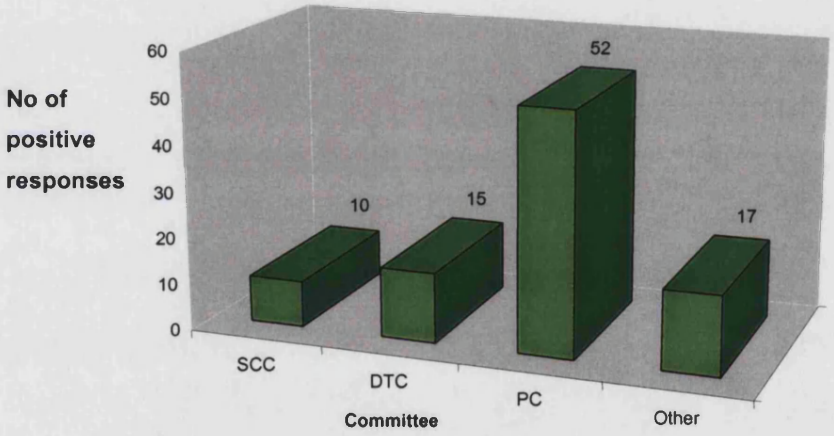
Figure 2.5, Health Authority Questionnaire – Mean Number of Shared Care Guidelines for Each Region (n=87)



2.2.5.1.3 Who Is Responsible For Agreeing And Implementing Shared Care Guidelines?

When asked "Who is responsible for agreeing and implementing shared care guidelines?", the majority replied that it was a Health Authority Prescribing Committee. Some HAs gave more than one answer to this question (Figure 2.6). There were 17 HAs who ticked the 'other' box, their answers are shown in Table 2.2. Some HAs agree these guidelines with other HAs in the region on an area or regional basis. Some Health Authority Pharmaceutical Advisers drew up guidelines and in other areas of the country guidelines were drawn up by the relevant Trust consultants.

Figure 2.6, Health Authority Questionnaire – Committee Responsible to Agreeing Shared Care Guidelines (n=87)



SCC = Shared Care Committee
DTC = Trust Drug and Therapeutics Committee
PC = HA Prescribing Committee

Table 2.2, Health Authority Questionnaire, Other Committees Responsible for Agreeing Shared Care Guidelines

Survey Number	Other committees responsible for agreeing and implementing Shared Care Guidelines
23	Committees can only draw up 'skeleton' protocols. Detail has to be between participating professionals and the patient. Having said that most of ours come from within the Trust and are individually 'tweaked'.
24	individual consultants
25	Normally done at the request of GP and done by consultants.
27	We have no panel which approves shared care guidelines but we do have a countywide Prescribing Policy Group which manages the introduction of new drugs
34	also other adhoc arrangements exist but ideally everything needs to go through the D&T
45	Local Area Prescribing Committee
46	Been developed ad hoc or by the MAAG
49	District Professional Committee, members of the local Trusts, HA and GPs
52	Agreed and produced regionally.
55	Regional committee for guidelines produced to date. Local Trust based groups.
62	Clinical Protocols Evaluation Committee
65	Pharmaceutical Adviser
67	HA prescribing committee for which drugs and overall policy. Trusts for implementation at a drug/condition level.
75	Health Authority Drug & Therapeutics Committee
101	Typically drawn up by GPs and consultants in association with other interested parties e.g. HA representatives, nurses, pharmacists, etc then adopted formally by the prescribing committees, LMC, HA, etc. For shared care we tend to develop disease based approach NOT drug based.
112	Clinical Guidelines Group
113	A subgroup of the area prescribing committee plus "experts" as necessary. All the donkey work done by the Pharmaceutical Advisers

The representation on the committee responsible for agreeing and implementing shared care guidelines is shown in Figure 2.7. The representation on the committees did not vary substantially between HAs. Most had Health Authority doctors and pharmacists, Trust consultants and pharmacists and GPs (often including Local Medical Committee (LMC) representation). Community pharmacists were not as commonly represented with 17 fewer committees having a Local Pharmaceutical Committee (LPC) representative than an LMC representative, although 5 HAs mentioned community pharmacists as other groups represented on the committee. Some (32) committees had contracts managers and administration staff, other members included 8 HAs who said there was a Community Health Council representative on the committee or a patient

(or lay view) and 5 who said there were finance staff on the committee. The designation of other representatives on the committee responsible for agreeing and implementing shared care guidelines are shown in Table 2.3.

Figure 2.7, Health Authority Questionnaire – Representation on Committee Responsible for Agreeing Shared Care Guidelines (n=87)

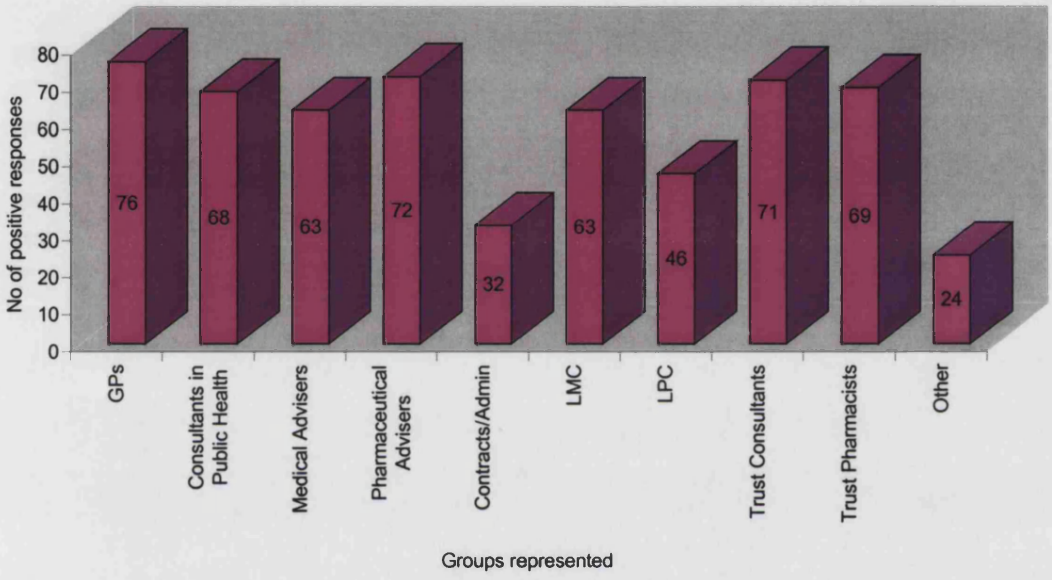


Table 2.3, Other Representatives on the Committee Responsible for Agreeing and Implementing Shared Care Guidelines, Health Authority Questionnaire

Survey Number	Other representatives on the committee responsible for agreeing and implementing shared care guidelines
6	Community pharmacists
23	patients, specialist and practice nurses
24	nurses, finance department
26	Non-executive director to present a lay view.
27	HA Director of Public Health, HA Finance
29	Community pharmacists
33	Patient representative from CHC
34	GP representatives, nursing representatives
36	D&T chairs, medical directors of Trusts
40	Drug Information Pharmacist, Community Pharmacists
42	Community pharmacist, pharmacist from local military hospital.
43	Representatives from groups with relevant interest invited (e.g. Alzheimer's Soc rep for donepezil). Primary Care Audit (HA), North Devon D&T Committee chairman
60	clinical pharmacologist
65	Health economist
66	Chairs of Trust D&T Committees, Trust formulary pharmacists/Interface Pharmacists
67	HA finance staff
69	Community pharmacists
70	hospital nurse
73	Medical advisers to HA also represent LMC and are GPs. Trust consultants and pharmacy representatives invited along to discuss specific issues, as are contract managers. Finance staff sit on committee as do Senior managers of the healthcare directorate.
74	Practice nurse
89	Community Health Council
96	To start:- CHC/ Ethics committee members
100	CHC rep, HA finance rep.
106	CHC
108	Trust consultants - as and when
109	CHC

CHC = Community Health Council

2.2.5.1.4 Successful And Difficult Aspects Of Shared Care Initiatives

The qualitative comments regarding successful and difficult aspects of shared care and further comments made on the subject of shared care are shown in Appendix 5. The coding of these comments by a group of three hospital pharmacists from Plymouth Hospitals NHS Trust, a group of Health Authority representatives and a group of Trusts finance staff as described in Section 2.2.4.4.3 is shown in Appendices 6, 7 and 8 respectively.

57 Health Authorities requested and were sent the summary of finding shown in Appendix 9.

2.2.5.2 Local GP Survey

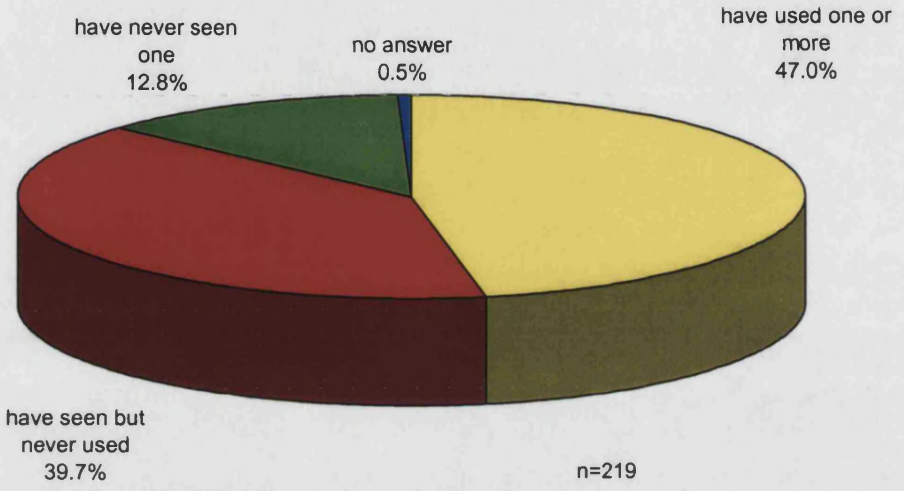
2.2.5.2.1 Response Rate

228 responses were received out of 357 questionnaires distributed (64%), nine of these were returned blank and were therefore unevaluable leaving a response rate of 219/357 (62%).

2.2.5.2.2 Familiarity With Local Shared Care Guidelines

190 (87%) of the respondents had seen a guideline produced by the South and West Devon, Cornwall and Isles of Scilly Shared Care Working Group. 47% had used one or more of the guidelines and 40% had seen but never used the guidelines (see Figure 2.8).

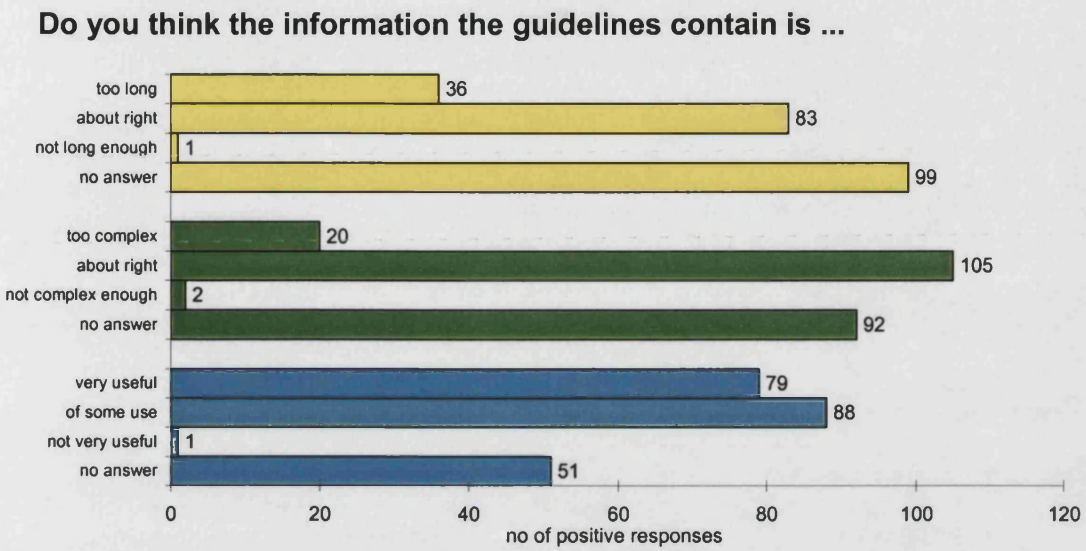
Figure 2.8, GP Questionnaire – Have you ever seen a Shared Care Guideline produced by the S&W Devon, Cornwall and Isles of Scilly Working Group?



2.2.5.2.3 Opinion Of Current Guidelines

Most GPs who answered questions about the usefulness, length and complexity of the guidelines available thought they were about the right length and complexity and "of some use" (Figure 2.9). Thirty-six (16%) GPs thought the guidelines were "too long", twenty (9%) thought they were "too complex" and only one thought they were "not very useful". Seventy-nine (36%) of the GPs thought that the guidelines available were "very useful".

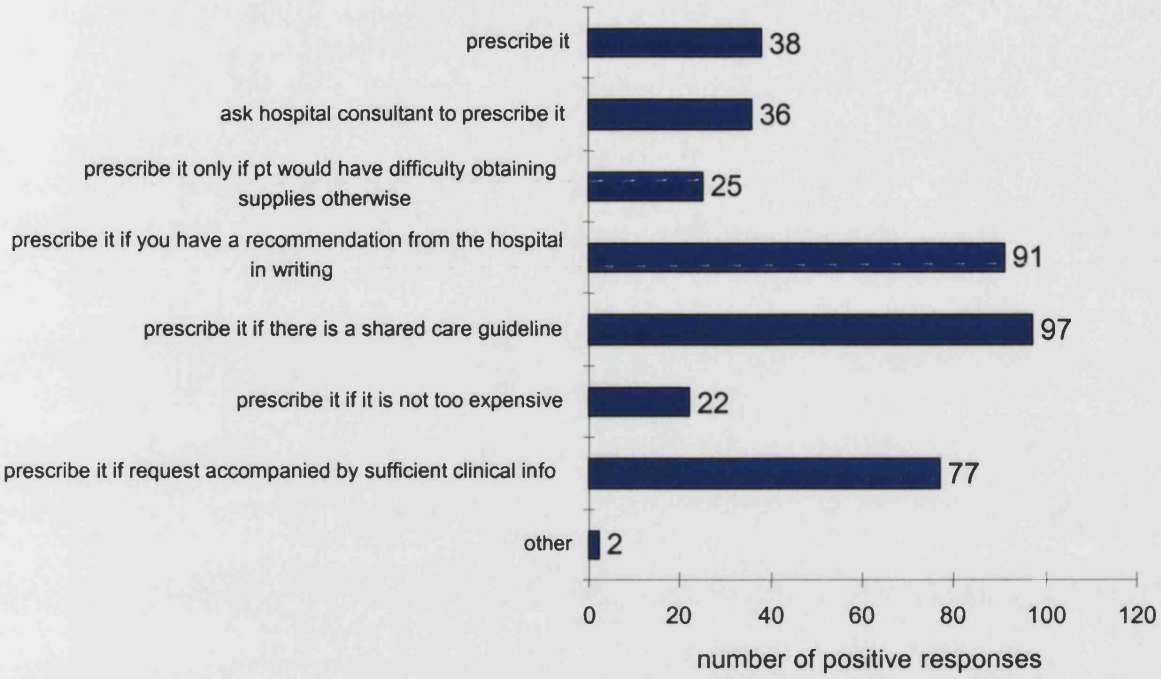
Figure 2.9, GP Questionnaire, What GPs think about the information the guidelines contain (n=219)



2.2.5.2.4 Prescribing Unfamiliar Drugs Recommended By A Hospital Consultant

Responding GPs (n=219) in South and West Devon preferred to prescribe a drug of which they had little experience, recommended by a secondary care colleague if a shared care guideline is available (97), if they have a recommendation from the hospital in writing (91) or if the request to prescribe is accompanied by sufficient clinical information (77) (Figure 2.10). 22 GPs said they would generally prescribe if it was not too expensive. Most GPs gave more than one answer to this question. Two ticked other, the first said they would "prescribe it if the hospital consultant continues to take overall responsibility for monitoring/dose adjustments" and the second said "I would only prescribe it if I felt happy to do so - bearing in mind if anything goes wrong 10 years later it would be the prescriber (i.e. the GP who signed the script) who would be wasting considerable time dealing with the resulting litigation. See for example the use of growth hormone contaminated with CJD - it took some years for this problem to come to light".

Figure 2.10, GP Questionnaire, (n=219) – If you are asked to prescribe a specialist initiated drug of which you have little clinical experience do you …



2.2.5.2.5 What Drugs/Diseases Would You Most Like To See A Shared Care Guideline For?

The answers to the question "what drugs, diseases would you most like to have a shared care guideline for e.g. risperidone, DMARDs?" are shown in Appendix 10.

The largest number of suggestions were for the two examples given, second line rheumatology agents and psychiatry drugs especially the new atypical antipsychotics such as risperidone and olanzapine. Methylphenidate, fertility treatments and cyclosporin were the next most requested drugs. Immunosupressive drugs, chemotherapy agents, gonadatrophin releasing hormone analogues, erythropoietin and drugs abused or used in drug and alcohol abuse were commonly mentioned.

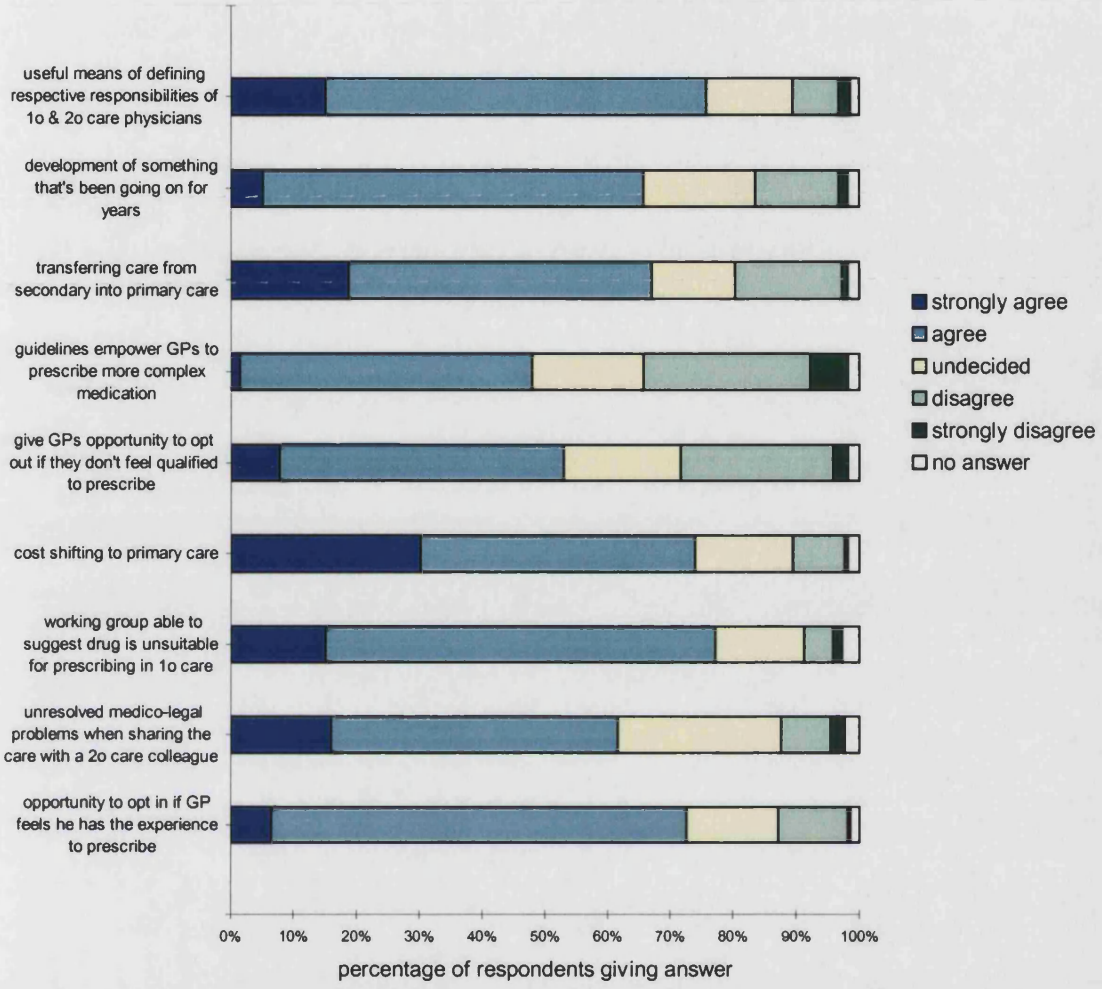
Nine GPs said "new" drugs and gave examples such as new anti-Parkinsonian therapies, drugs for dementia and drugs used to treat male impotence, eight said drugs which are initiated in secondary care of which GPs have little experience,

eight mentioned expensive drugs, six said they didn't want any more and four said they would like guidelines for drugs which needed monitoring.

2.2.5.2.6 Opinion Of GPs On The Concept Of Shared Care

The results of Section 2 of the questionnaire are shown in Figure 2.11. The statement that most GPs strongly agreed (66) with was that "shared care is about cost shifting to primary care". The largest number in agreement ("strongly agree", 33 + "agree", 136 = 169) was with the statement that "the shared care working group is able to suggest that a drug is unsuitable for prescribing in secondary care". More GPs (14 "strongly agree" + 145 "agree" = 159) felt that using shared care guidelines gives them the opportunity to opt in to sharing the care of a patient for whom they do have the experience to prescribe than felt that shared care guidelines give them the opportunity to opt out of sharing the care of a patient for whom they do not feel qualified to prescribe ("strongly agree" 17 + "agree" 99 = 116). The statement that the greatest number of GPs disagreed with (both "strongly disagree", (13) and total of "disagree" and "strongly disagree", (71) was that shared care guidelines empower GPs to prescribe more complex medication.

Figure 2.11, General Practitioner Questionnaire – Views of General Practitioners on the Concept of Shared Care (n=219)



N.B. 1o = primary and 2o = secondary.

62 GPs gave further comments regarding shared care, which are shown Appendix 11. They were coded as described in Section 2.2.4.4.4. The results of the coding exercise are shown in Table 2.4.

Table 2.4, Coding Of Further Comments From GPs

Category	Sub-category	Number of responses
Workload shift	general	3
	resourced	0
	not resourced	9
Funding transfer for drugs	general	4
	not organised	10
	agreed mechanism	0
Best care		1
Format of guidelines	general	1
	positive	0
	negative	4
Concern about responsibility transfer from secondary to primary care		16
Knowledge base	general	0
	positive	1
	negative	1
Comments on questionnaire	general	0
	positive	1
	negative e.g. no time to complete	5
Risk transfer		4
Concept of Shared Care	general	2
	positive	3
	negative	9
Answer not relevant/coded		15

Sixty-seven GPs requested and were sent the summary of findings shown in Appendix 12.

2.2.6 Discussion

2.2.6.1 Health Authority Survey

2.2.6.1.1 Response To Questionnaires

A good response rate was achieved with this questionnaire (87%). This could have been attributed to the fact that Health Authorities received both written and telephone reminders on a number of occasions. It may also have helped that the questionnaire was, in most cases, distributed personally by the researcher with some sort of presentation or explanation of the objectives of the project. The range was 71% (North Thames), where 4 of the 14 HAs did not respond to 100% (South and West) of questionnaires sent returned*.

There was no sample bias as the whole population of Health Authorities in England was included in the study. Response bias may have occurred, as non-responders may not have had any involvement with shared care or HTHH and for this reason did not return the questionnaire. As the response rate was so high this effect should be minimal. There was no obvious pattern to the non-responders.

2.2.6.1.2 Geographical Distribution

It can be seen from Figure 2.5 that the mean number of guidelines was similar in all of the regions (standard deviation 0.87). The mean number of guidelines per HA at any stage of development was six. The North Thames region, which had the highest proportion of non-responders also had the smallest mean number of shared care guidelines (Table 2.1 and Figure 2.5).

2.2.6.1.3 Subject Of Guidelines

It can be seen from Figure 2.3 and Figure 2.4 that shared care guidelines are being produced for the newer, higher cost therapies rather than those disease states such as rheumatology and diabetes where informal shared care has been practised extensively for many years. Erythropoietin was by far the most common subject of a shared care guideline followed by cyclosporin, dornase

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* The regions used are those which existed when the surveys were carried out prior to the change of boundaries in April 1999.

alpha, the interferons, donepezil, riluzole and infertility treatments. Growth hormone was the most common subject of a guideline that was not covered in the list in the questionnaire. The introduction of the newer, more expensive recombinant product has probably prompted this. These data combined with those in Section 2.2.6.1.5 suggest that shared care is playing an important part in the managed entry of new drugs into the NHS.

2.2.6.1.4 Who Is Responsible For Implementing Shared Care Initiatives?

It appears that it is the Health Authorities who are facilitating the development of shared care guidelines for interface prescribing, bringing primary and secondary care representatives together at Health Authority prescribing committee meetings. 52 HAs said it was a HA prescribing committee who were responsible for agreeing and implementing shared care guidelines, 10 had a separate shared care committee, 15 used the Trust Drug and Therapeutics Committees, as suggested in EL(91)127 [19], and 17 used a variety of other committees usually specific to their area or stated that GPs and consultants draw them up between themselves. The view was also expressed that it should be up to the consultant and GP to set up a shared care procedure on an individual patient basis.

One concern of GPs with shared care initiatives is that of cost shifting [19] (later discussed in Section 2.2.6.2). It is interesting that a number of committees feel it useful to have finance staff represented, possibly to suggest solutions such as high cost drug contingency funds or virement of money from primary to secondary care or *vice versa.* 5 Health Authorities mentioned virement projects and in the comments regarding successful and difficult aspects of shared care the view was commonly expressed that expensive therapies were difficult to get agreement on whereas cheaper therapies were easier.

2.2.6.1.5 Successful And Difficult Aspects Of Shared Care

Although this survey was aimed at collecting quantitative information the two open questions included provided more depth to the data collected. Triangulation of the coding of the qualitative data by three different groups of staff was employed as described in Section 2.2.4.4.3. It was decided that if a coding frame were developed from the data prior to the groups coding it bias

would be introduced. It was therefore left to the groups to develop a coding frame using grounded theory [107]. In this way they coded into categories which they felt were important subject areas drawn from the raw data. Depth of the data would be maintained and by comparing the coding frames developed the major concepts could be identified and triangulated.

The data were difficult to code and the three groups took different approaches. It was interesting that whereas the hospital pharmacists and Health Authority coding groups put emphasis on differentiating the comments regarding cost, the staff from finance grouped all comments regarding cost into one category. The Health Authority group went through the data twice, first extracting all the comments about cost and developing a coding frame for those, and then drawing up a second coding frame for the remaining data (Appendix 7).

Table 2.5 compares the coding frames of the three groups. It can be seen from this that although the groups took different approaches to coding the data twelve common themes were identified. There were few codes developed by one group that were not mirrored by the other two groups. It can be seen that the groups developed very similar categories thereby validating the inductively derived concepts. Most of the categories used by the groups were split into negative and positive comments or successful and difficult aspects, adding dimension to the coding of the data. The Health Authority group took this further developing further sub-categories.

Table 2.5, Coding Frames developed by the Groups

	Health Authority	Finance	Pharmacy
Communication/Collaboration	joint approach GPs, trusts, HAs qualitative improvements - communication, collaboration, relationships, wider knowledge, involvement	collaboration, liaison, communication (successful) poor communication (difficult) poor collaboration (difficult)	co-operation, communication, debate, time practicalities HA↔primary care↔secondary care ↔tertiary care↔HA etc
Framework/ infrastructure	infrastructure, process	clear guidance framework (successful) lack of clear guidelines (difficult)	framework - appropriate drug for primary care prescribing, needs a protocol, drug selection comment on generic guidelines
Specific drug/ disease	specific drug/disease area	specific drug	specific drug/diseases
Finance	cost cost shifting cost (total) cost irrelevant cost effectiveness non drug payments	financial, cheap (successful) financial (difficult)	money general joint transfer funding cost shifting
Education	qualitative improvements - communication, collaboration, relationships, *wider knowledge*, involvement	education (successful) lack of education, knowledge, training (difficult)	education - GP provided with information
Tertiary centres	tertiary referrals	tertiary centre (difficult)	co-operation, communication, debate, time practicalities HA↔primary care↔secondary care ↔*tertiary care*↔HA etc
Responsibility	clinical responsibility	reluctance to accept responsibility (difficult)	Medico-legal responsibility
Implementation	usage implementation positive comments negative comments	negative comments (successful) too difficult - individual difficulties not specified failure to obey guidelines (difficult)	not used, not successful
Audit/evaluation		evaluation, audit (difficult)	audit - comment on need to evaluate
Managed entry of new drugs	managed entry of drugs	managed entry of new drugs	
Defining shared care	definition of shared care		principle of shared care, what it means, how interpreted
No comment/not sure	uncertain	no comment/unsure (successful) no comment (difficult)	early stages, no data to comment on yet
		(increased paperwork?)	politics, general comment on bureaucracy rationing, political environment
	evidence based practice		
	contracting		
	patient's convenience		
	(non-drug payment)		shared vs transfer of care comments on transfer
			patient selection who gets what

It can be seen from the Appendices (6, 7 and 8) that the Health Authority and hospital pharmacist groups coded the data into the frame they had developed whereas the finance group came up with a coding frame but did not have time to code their data into it. The most common concepts developed from the data by the three groups are discussed below.

2.2.6.1.5.1 Finance

There were numerous comments regarding financial issues around shared care and from these data this appears to be one of the major problems encountered in shared care initiatives. Comments such as those shown in Box 2.1 were common.

Box 2.1

"Often seen purely as a cost shifting exercise from secondary to primary care".
"Many of the GPs still feel it is "cost-shifting" from the hospitals"
"When is it shared care? When is it cost-shifting?"
"Attitude is often "I am a consultant, so do as I say and prescribe drug x because the hospital cannot afford it!""

Various methods are being used in an attempt to overcome this. Virement projects where money is vired from primary to secondary care and *vice versa* to follow prescribing have been tried. Some HAs keep contingency funds to try and cover the cost of these therapies in primary care so that shared care may be taken on by a practice without it taking on the cost of the drug. However the money still ultimately comes from primary care funds.

There was a feeling that shared care would be more easily agreed once unified prescribing budgets become a reality (Box 2.2). This may happen with the introduction of Primary Care Groups of Levels 3 and above. It may be that the GPs decide they would rather prescribing remained in secondary care. Practically, with tertiary referral centres and patients living a long way from their secondary provider GPs will inevitably be prescribing some complex hospital

initiated therapies unless a mechanism is developed to overcome this. It is hoped that the true debate about clinical and therefore prescribing and medico-legal responsibility for various therapies will then be able to take place without being clouded by the financial implications to either provider. PCGs are still very young organisations and PCTs even more so. The unified budget has become a reality in the way that HAs allocate resources to the PCG/PCTs. However, it will take time for the PCGs to gain experience of commissioning and to develop novel approaches to make the best of this unified budget. In the first year of PCGs commonly historic indicative budgets were uplifted and the unified budget had little effect. This may change in the second year of PCGs some of whom have now moved to PCT status with the effect of cash limited budgets for prescribing for the first time. Many of the PCGs will have overspent their primary care prescribing budgets and will be looking to find resource from other areas to support prescribing. This is another factor which may be preventing GPs from taking on the prescribing of hi-tech and often high cost drugs in the community.

Box 2.2

" May become more meaningful when unified budgets are in place."
"Unlikely to work properly until all funding in same pot."
"Life may be easier if we had joint primary and secondary care prescribing budgets!!"

Another issue that came both from these data and those obtained from the survey of local GPs (Section 2.2.5.2.) was the lack of funding for the extra workload associated with shared care in addition to increased pressure on prescribing budgets (Box 2.3).

Box 2.3

"LMC core/non-core payment for work undertaken."
"The whole area of shared care seems to have become caught up in the "core –non core political debate."

2.2.6.1.5.2 Communication and Collaboration

Both groups that coded the data showed that there were more difficulties with communication and collaboration than successes. Although, in general the development of shared care guidelines was seen to enhance communication between primary and secondary care and it was lack of communication that was perceived to prevent the successful development and implementation of the guidelines. Examples of both successful and difficult aspects are shown in Box 2.4.

Box 2.4

Successful Aspects

"The process of developing agreed approaches to disease management between specialists and generalists (both GPs and non-specialist consultants) has opened communications between these groups on many fronts. It has provided a useful cornerstone to developing the input of professionals into Trust and HA management".

"Collaboration has improved communication and ensured equity of care".

Difficult Aspects

"Getting people to meet, let alone try and agree".

"Hospital attitude is a serious problem, they do not put forward proposals but try and impose their ideas.".

It may be that with improving electronic communication between health professionals in a much more timely manner than is currently the case, there will be at least the facility for better communication and collaboration between primary and secondary care. The introduction of the NHS-net should help facilitate this but it will be a number of years before this is available in all General Practices as not all are computerised. The development of NHS-net could eventually lead to one set of medical records being held for each patient rather than having a different set of records in primary, secondary and sometimes also in tertiary care. Wright [79] points out that joint records seem acceptable to patients but less so to their doctors.

It is also a change in attitude and way of working together that is required. Shared care guidelines do, in places, seem to have had a beneficial effect on this relationship. They lay out the various responsibilities in a structured way helping health care professionals in both primary and secondary care to know exactly where their respective responsibilities lie when care is shared. Their existence does not solve the ongoing problem of lack of timely and accurate communication between health care professionals.

2.2.6.1.5.3 Responsibility

One of the major problems with sharing the care of a patient is taking over the prescribing of a complex and often unfamiliar drug by the GP. In signing the prescription the GP is accepting clinical responsibility [20]. Hospital consultants often do not seem to appreciate this as can be seen from the comments in Box 2.5.

Box 2.5

Difficulty "Getting the consultants to understand that prescribing and clinical responsibility are attached, not separable."
"Lack of acceptance that GPs hold responsibility for prescribing."
"Still there is a view that GPs will automatically take on the prescribing for all drugs regardless of the clinical responsibility issues".
"View of hospital consultant of "why should we have to discuss/agree this with GPs in advance. We just tell them and they should prescribe it"!!!"

This is supported by an audit conducted by Brighton University [106] where hospital consultants were interviewed. The consultants' perceptions of shared care included the following:

- GP concerns about clinical responsibility were sometimes used as a smoke screen for more predominant budgetary concerns.
- GPs have a duty to prescribe for their patients in the community and refusal to participate in shared prescribing of hi-tech medicines may represent an abdication of this responsibility.

- Relatively few saw the need to discuss arrangements on a personal basis with individual GPs.

Advice obtained from the Medical Defence Union [108] states that "there is no doubt that legal responsibility for prescribing falls to the doctor who signed the prescription". This was also made very clear in EL(94)72 (5). So it remains that if a GP does not feel qualified to prescribe the drug and is not willing to take legal responsibility for the prescription they should not prescribe. However they may decide to accept an arrangement whereby they share the care of the patient without prescribing, such as in the case of a patient receiving a home TPN or antibiotic infusion [99]. The current situation is that the GP can be in a very difficult position if for example they are asked to prescribe a drug by a tertiary centre (see Section 2.2.6.1.5.4.), they may have to explain to the patient their reasons for not wanting to prescribe. The patient may well not understand that this is in his or her own interest. After all, where else will they obtain their drugs?

It has recently been suggested [20] that a change in the law could allow a GP to prescribe as consultant's deputy. The consultant could give written authorisation for a GP to repeat prescribe while agreeing to maintain clinical responsibility for the patient. Another solution suggested was that a consultant prescription could authorise repeat dispensing from a community pharmacy. The Crown Report [109] has also suggested a distinction between categories of prescriber "independent" and "dependent". GPs could potentially take on the role of dependent prescriber when prescribing on behalf of a hospital consultant.

2.2.6.1.5.4 Tertiary Centres

Setting up shared care arrangements between GPs and tertiary centres was a problem (Box 2.6). It is commonly going to be the case that a tertiary provider will be geographically distant from the patient's home. It is not practical for the patient to collect prescriptions from the hospital pharmacy and often the GP is asked to continue therapy of which he has very little other input or understanding. It is very difficult for the GP to refuse to prescribe. It may not be

advantageous to ask a consultant from the local hospital to prescribe because they may have no other clinical input and this can lead to further communication problems with more people involved.

Box 2.6

"Tertiary centres cause the problems most, especially communication on issues about prescribing responsibility. It doesn't really work"

There is not an easy answer to this as ownership of shared care guidelines is often key to their acceptance and it is obviously not possible for all of the GPs who may potentially be asked to take on prescribing and care of the patient from the tertiary provider to agree the guidelines. It seems that it would nevertheless be useful for these centres to produce guidance for a GP who chooses to accept responsibility for this type of patient. The agreement would then have to be made on an individual basis between the GP and the specialist centre. This has the disadvantage for the tertiary centre in that it is difficult to have varying arrangements with many different GPs. It might again be that the ideas of prescribing as a consultants deputy, dependent prescribers or having consultant repeat prescriptions dispensed from community pharmacies would be a useful solution but would require changes to be made to current NHS legislation. Training of community pharmacists would also be required so that they are not dispensing medicines, which are unfamiliar to them and for which they cannot provide appropriate pharmaceutical care.

This is perhaps an area that PCGs and PCTs should be looking at as part of their commissioning arrangements with tertiary centres. FP10(HP) forms have been used in some areas to allow hospital practitioners to prescribe drugs for patients when the clinic is held away from the hospital pharmacy. These can be dispensed by community pharmacists and are charged to the NHS Trust. A problem with FP10(HP)s is that it is currently difficult to monitor prescribing using these prescriptions as the Prescription Pricing Authority do not produce Prescribing Analysis and Cost Data on them.

2.2.6.1.5.5 Framework/Infrastructure

There were several comments regarding agreeing an infrastructure or processes for implementing shared care initiatives. The view was held in some cases that detail of a shared care arrangement should be agreed between the consultant and the GP concerned on a patient by patient basis. Some of these Health Authorities produced generic guidance to be followed when drawing up an individual arrangement. Others favoured making decisions as to whether drugs were suitable for prescribing in primary care (Box 2.7). Two Health Authorities mentioned a traffic light approach where drugs were classed as red- hospital only, amber- initially hospital only for a specified period or green-suitable for prescribing in primary or secondary care.

Box 2.7

"...we have a pilot running in which the GP drugs budget has been top-sliced and money is given to the consultants to provide drugs which should be consultant prescribed."

2.2.6.1.5.6 Managed Entry Of New Drugs

EL(94)72 [21] suggests that shared care initiatives can form a part of the process of the managed entry of new drugs. It appears that at least in some Health Authorities this has been the case (Box 2.8). Many shared care initiatives include agreement on whether drugs are suitable for prescribing in primary care, this helps the managed entry of drugs into primary care and complements the work of Drug and Therapeutics Committees in secondary care. The main aim of shared care [19, 21] must still be to improve patient care by improving the patients understanding of their therapy and improving communication between professionals jointly responsible for their care, making sure that there is a clear framework of where respective responsibilities lie.

Box 2.8

successful aspects

"very few, except now we have our act together about new drugs"

"Developing shared care guidelines is an important part of this Authority's approach to the managed introduction of new drugs and technologies.".

2.2.6.1.5.7 Specific Drug/Disease

Many of the comments regarding which aspects of shared care had been successful and which had been difficult were answered with specific drugs or diseases Box 2.9.

Box 2.9

Successful Aspects

"Home Parenteral Nutrition"

"donepezil, riluzole, infertility"

Difficult Aspects

"Prescribing issues in mental health currently proving to be difficult. General reluctance to take on shared care for certain groups of mentally ill patients following publication of GMSC paper "Mentally Disordered People: Continuing Care in the Community". Fertility issues cause general problems because of the difficulty of private services."

"Areas such as beta interferon where the local consultants don't wish to use the drug."

There was no consensus on this and it appeared to be where agreement had been reached and the guidelines had been successfully implemented, this drug or disease was considered successful and where problems had arisen in reaching agreement and there had been poor uptake of the guideline this was considered problematic. For example different Health Authorities listed β-interferon as being both successful and difficult.

2.2.6.1.6 Shared Care for HTHH

There were some shared care guidelines for HTHH. These would involve a model of shared care different from most of the examples given as the GP would not be taking on prescribing responsibility for a patient receiving a home infusion under EL(95)5 [41]. There were nearly as many shared care guidelines for home antibiotic infusions (14) as home TPN (15) which was surprising considering many more of the Health Authorities contracted for home TPN than for home antibiotic infusions (section 2.2.5.1.2. and Chapter 3).

2.2.6.1.7 Limitations

The main limitation of this work is that it has taken one perspective, that of the Health Authorities, and therefore may have missed shared care initiatives in which the Health Authority has little involvement and where Trusts or local GPs are taking the lead. However the responsibility for facilitating shared care initiatives was given to the Health Authorities in the form of EL(91)127 [19] and EL(94)72 [21]. It would therefore be the exception rather than the rule that a Health Authority adviser would be unaware of shared care initiatives in their area. This is not an in depth analysis of the different models used in shared care initiatives and their relative effectiveness but gives an overview of the current position and identifies the main factors having an influence on shared care initiatives at the primary secondary care interface.

2.2.6.2 Local GP Survey

2.2.6.2.1 Response Rate

The response to the survey was pleasing when compared to response to other surveys distributed in a similar manner in the past by the Health Authority to the GPs in South and West Devon. The results of this survey are obviously not representative of all GPs but look specifically at the situation in South and West Devon. There was no sample bias of this defined population as again the whole population was included in the survey. Response bias may have had a greater impact on this survey as it may have been that GPs who were unfamiliar with the shared care guidelines produced by the SCWG were less inclined to complete the

questionnaire than those who had seen or had experience of using them.

2.2.6.2.2 Familiarity With The Guidelines

The dissemination of the guidelines to all GPs in South and West Devon was a successful way of ensuring that most GPs were aware of the guidelines. Even if it were assumed that all of the non-responders have never seen a guideline produced by the SCWG most GPs (54%) in the area would be familiar with them.

2.2.6.2.3 Content of the Guidelines

Nearly half of the GPs (47.0%) who responded to the questionnaire had used one or more of the guidelines. This suggests that they are useful and this is confirmed by the fact that 79/219 GPs rated them as "very useful" and 88/219 rated them "of some use". From these data (Figure 2.9) it seems that the consensus is that the complexity of the guidelines is "about right", and should not be made any more complex. 20/219 GPs thought they were "too complex". The majority thought they are about the right length but there were 36/219 who said they were "too long" suggesting that the SCWG should not make guidelines any longer and should reduce the length where practical.

2.2.6.2.4 Prescribing Unfamiliar Drugs Recommended By A Hospital Consultant

The question regarding prescribing unfamiliar drugs recommended by a hospital consultant was asked partly to assess whether the GPs were under the false impression that the hospital specialist was able to retain medico-legal responsibility even if the GP was signing the prescription. Most GPs gave more than one answer to this question.

GPs are more comfortable prescribing in this situation if a shared care guideline is available. This is possibly because they feel that prescribing within the recommendation of a guideline agreed locally by specialists in the field and agreed by a multidisciplinary committee, would be easy to defend in a medical negligence case. It might be easier to prove that the action taken was "capable of support from an informed reasonable body of clinicians of similar training and

experience" [108]. It should be noted that the GP still retains clinical responsibility for the prescription when prescribing in line with a shared care guideline.

Ninety-one GPs said they would prescribe it if they "had a recommendation from the hospital in writing". This suggests that they feel they would be able to defend their prescribing with evidence that the recommendation came from a hospital specialist. This may be the case but does not give them the "opinion of a reasonable body of clinicians" and again by signing the prescription they are accepting clinical responsibility. In a similar vein 77/219 said they would prescribe if the request was accompanied by sufficient clinical information. This might be that they would require enough clinical information to base their own informed decision on whether to prescribe and therefore take clinical and medico-legal responsibility. It is perhaps worrying that more GPs said they would just "prescribe it" (38) than said they would "ask the hospital consultant to prescribe it"(36). Reassuringly there were relatively few GPs (22) said that they would prescribe it if it was not too expensive which suggests that cost is not a major consideration when accepting shared care arrangements. There may have been some bias in that the GPs were unwilling to admit this as they were aware that the results were being fed back to the SCWG (Hawthorne effect [110]).

The problem of tertiary centres raised in the Health Authority questionnaire (Section 2.2.6.1.5.4.) may lead to patients having difficulty obtaining supplies of complex therapies if their GP does not prescribe them. Twenty-five GPs said that they would prescribe if "the patient would have difficulty obtaining supplies otherwise". This is often a very difficult position for GPs as there is an emotional response from the patient if the GP is considered to be hindering their therapy in any way. By virtue of the fact that the patient has been referred to a tertiary centre the problem is often serious and it is important to maintain a good patient-GP relationship. However the GP will probably not be familiar or feel able to take clinical responsibility for drugs initiated in tertiary settings.

2.2.6.2.5 Subject Of Further Guidelines

GPs would most like shared care guidelines for newer, more expensive therapies of which they have little experience and which may need monitoring. Areas where guidance was not as clear as it might have been, such as drugs used in the treatment of drug and alcohol abuse and fertility treatments, were also commonly requested. In 1999, after this survey was carried out, national guidelines for shared care of drug users were published by the DOH (www.doh.gov.uk/ drugdep/htm). The information shown in Appendix 10 was fed back to the SCWG. Some GPs pointed out that it was precisely the drugs that they didn't know about that they most needed shared care guidelines to cover. It is therefore useful that the SCWG has a dual approach whereby the Area Prescribing Committee refers new drugs for the development of guidelines and GPs request guidelines for drugs with which they are familiar.

2.2.6.2.6 GP Views On The Concept Of Shared Care

The GPs in South and West Devon consider that the SCWG has the authority to decide which drugs are unsuitable for prescribing in primary care and make this recommendation. This is one solution to the problem but is not commonly adopted throughout the country (section 2.2.5.1.3). It might be that Primary Care Groups will want more prescribing of these specialist initiated therapies to stay in secondary care and they may well vire money into secondary care prescribing budgets to ensure that this happens.

In line with the Health Authority survey and also with a survey which used structured interviews to obtain the opinions of GPs on shared care [106] one of the major problems identified is that shared care is seen by GPs as a cost shifting and workload shifting exercise by secondary care.

61.6% of respondents agreed that there are "unresolved medico-legal problems when sharing care with a secondary care colleague" (35 "strongly agree" + 100 "agree"). The largest number (57) of "undecided" answers were given to this statement. It is of concern that GPs are not aware of the medico-legal responsibility they are taking on when agreeing to take part in shared care arrangements.

Interestingly more GPs felt that shared care guidelines gave them the opportunity to opt into sharing care if they feel they do have the experience to prescribe than to opt out if they don't feel qualified to prescribe. This question was originally intended as a validation question but it is apparent that GPs find it more difficult to opt out of shared care than opt in. It has been reported to the SCWG that when a GP has declined to share care they have been pressurised by the consultant to change their mind. This is a situation that is obviously not acceptable and must be resolved if shared care initiatives are to be successful.

Another common concern raised by local GPs was that of transfer of clinical responsibility from secondary to primary care. This is in line with the national situation identified in the Health Authority survey (2.2.6.1.5.3). There were also comments that the funding for shared care was not organised and that consequent workload shift was not funded. Nine GPs who commented on the concept of share care gave negative comments.

The results of this survey are in line with the University of Brighton audit, which interviewed GPs to elicit their perspectives of current shared care arrangements [106]. This study found that GPs felt that prescribing of hi-tech medicines was not truly "shared" as the GP is prescribing from a position of relative ignorance about the medication which leads to concerns about clinical management and possible litigation. GPs saw the main motive for sharing care as cost shifting from secondary to primary care budgets. The concerns of the South and West Devon GPs about workload shift and lack of funding for this in addition to prescribing costs were however not reported in the Brighton study. Their emphasis was much more on appreciating a personal approach from the consultant preferably by telephone rather than letter. GPs in South and West Devon did not show as much dissatisfaction with the type of information that they receive. As the Brighton survey took a sample of GPs from a region rather than a local Health Authority area it is not clear what "current" shared care arrangements were in place.

2.2.6.2.7 Limitations of GP Survey

This work was only concerned with one side of the shared care partnership, that of the GPs. In order to conclude that this model of shared care is successful the opinion of hospital consultants would have to be sought and the patient outcomes monitored. It is a very local survey looking at arrangements peculiar to South and West Devon and care should be taken in extrapolating the views of this small number of GPs on the situation in South and West Devon to the rest of the country. However, the views of this sample of GPs do seem to be in line with those expressed in the literature (2.1.3.5).

In order that a good response rate was achieved the questionnaire was kept short and therefore in depth information was not obtained. A tick box style of questionnaire was used to reduce the time and effort required to complete the questionnaire. This may have led to bias in opinions as they had to be predicted to be included in the tick box responses and the GPs may not have expressed these views if they had not been prompted by the questionnaire. Sixty-two GPs did however contribute more than the minimum requested in the questionnaire by adding their further comments.

2.2.7 Conclusion

The local procedure for the development of shared care guidelines in South and West Devon appears to be successful. They do, for the most part, fulfil GP expectations and GPs are reasonably happy with them. This work has established that the major concerns of GPs about shared care are over cost shifting, lack of funding for the associated shift of workload from secondary to primary care and taking on clinical and therefore medico-legal responsibility for the patient. The results of this survey have been fed back to the SCWG. The future working agenda has been drawn up from Appendix 10 of this project. Comments of the GPs on the design of the guidelines will be noted when future guidelines are drawn up.

Shared care initiatives have been implemented successfully throughout England using various models. There have been few shared care guidelines/protocols

produced. The greatest successes have mostly been for complex, new and high cost drugs, often to manage the entry of new drugs and broker an agreement between primary and secondary care on prescribing responsibility. Health Authority led prescribing committees have, in the majority of cases, been responsible for the development and implementation of shared care guidelines.

Shared care does appear to play a useful role in managing the entry of new drugs into the NHS as intended by EL(94)72 [21]. The perception of cost shifting has been a major barrier to the implementation of shared care initiatives but this may become less of a problem if unified budgets become a reality with the new Primary Care Groups and Primary Care Trusts. It remains to be seen what differences some of the changes in GP Terms of Service will bring about as more practices move to Personal Medical Services contracts rather than the traditional General Medical Services contracts.

There are concerns regarding clinical and medico-legal responsibility when GPs enter into shared care arrangements. These cannot be readily overcome but this may come a step closer with review of legislation following the Crown [109] report. It is crucial that communications and collaboration between primary and secondary care health professionals are improved if shared care initiatives are to be successful.

Increasingly expensive drugs and higher expectations partly raised by the government's clinical governance initiatives, promises to end postcode prescribing and the National Service Frameworks mean that managing the entry of new drugs into the NHS has been difficult. The National Institute for Clinical Excellence is facing more appeals than were expected and patient pressure groups are leading media campaigns to pressurise the government into making drugs available on the NHS. A recent example of this is the NICE technology appraisal on beta-interferon for multiple sclerosis (www.nice.org.uk.

The challenge is not just who is the most appropriate clinician to prescribe but how will advances in drug therapy continue to be funded. In 2000 Alan Milburn the Minister for Health announced a plan of increased spending on the NHS but

much of the finance is non-recurring and linked to specific government targets (Department of Health Press Release, 2000/0666). Unified budgets may eventually herald the end of shared care being considered as cost shifting but they will not solve the problem of how these hi-tech therapies will be afforded. Individual Health Authorities and PCTs will still have to prioritise funding. This was recognised by the Royal College of Physicians in their working party report "The Prescribing of Costly Medicines" [22] which recognised that unless certain treatments are disallowed on the basis of cost, the quality of health care must suffer.

This debate has been raised in the treatment of Gaucher's disease with alglucerase [111]. GPs may be happy to share care or it may be more appropriate for an outreach team or commercial provider to care for the patient but funds must be identified to pay for this care. Moving the provision of some of these hi-tech infusions to the community setting has been used as a way of reducing overall health costs to afford new therapies in countries like the United States by health insurers.

As new, more effective and higher cost treatments become available the NHS must seek to reengineer the way care is provided to provide a patient centred health service making use of new technologies but ensuring that patients have access to the appropriate expertise. It may be, in the future, that developments in telemedicine, electronic conferences and data transfer via modems will enable GPs or hospital outreach staff and their patients to gain access to specialist advice and support from the community setting and there will be less need for patients to travel to hospitals for their care. An area where this has begun to happen in the UK is in the delivery of home infusions. It was therefore decided that this study should investigate the development of home infusion therapy in the NHS in England in more detail.

3 Hi-tech healthcare at home

3.1 Literature Review HTHH

The term "hi-tech health care at home" (HTHH) has been used to describe those treatments described in EL(95)5 [41] which usually require special compounding and complex administration techniques. This can be considered to range from continuous ambulatory peritoneal dialysis and enteral nutrition (both outside the scope of this project, as they were later excluded from EL(95)5 [41]) to the administration of intravenous parenteral nutrition, chemotherapy and other drugs. There has been much technological advancement over the past 20 years in intravenous access, infusion devices and drug therapy which has made it possible for infusions to be administered safely to patients in the domicillary setting. Patients have been proved well able to manage infusion therapy at home as long as appropriate patient selection, training, back up and quality assurance are employed in a home care scheme [7, 8, 112-115].

In 1970 Scribner et al [116] described the first home infusion. They gave details of an artificial gut system for patients incapable of enteric feeding. They reported a case where a patient had concentrated nutrients introduced into the circulation via an arterio-venous shunt, either delivered in the daytime by a portable pump or at night by gravity feed. The system was operated by the patient in his own home. This programme offered major advantages to the patient over conventional parenteral nutrition in that he received his entire fluid and calorific requirements over 10-12 hours allowing time to pursue other activities.

Since then the home infusion market has grown enormously, particularly in the United States but also in Canada [27, 117-120], Australia [35, 121, 122], Europe [99, 123-127] and Japan [33, 34]. Patients receive many different infusions safely and cost effectively in the home care setting including antibiotics [128], anti-virals [25, 129], chemotherapy [127, 130], pain relief [131, 132], apomorphine [11] and immunoglobulins [9].

Winters [133] reports that, Rucker and Holmstead's estimate of home infusion industry revenue, in the USA, in 1983 was $265 million. They forecast that it would grow to more than a billion dollars by 1988. In fact it had grown to over $1.5 billion by 1988 and to $4.2 billion by 1993, although the compounded annual growth rate shrank from 58% per year between 1982 to 1987 to 13% per year between 1991 and 1993 [133].

During the early eighties in a cost containment exercise in the United States, Medicare introduced its prospective payment system based on Diagnosis Related Groups (DRGs) which introduced an economic pressure to reduce hospital length of stay [133, 134]. Payers began to see the financial benefits of providing healthcare at home as it reduced cost of care due to the lack of need to pay hotel fees.

During the huge growth of the home infusion market, in the USA, in the1980s many commercial providers of home infusions emerged and the number of hospital pharmacy departments providing home infusions declined. Winters [133] reports that the key to the success of these companies was the nursing services they provided. Nurses were recruited from acute care hospitals and instructed patients and their carers on infusion techniques prior to discharge and made home visits on a regular basis after discharge to provide necessary monitoring and surveillance. Since a low was reached of approximately 17% in 1989, the number of hospital pharmacy departments providing home infusions started to rise to 26.9% in a survey in1990 [135].

3.1.1 Home intravenous antibiotic therapy

3.1.1.1 History

3.1.1.1.1 Cystic fibrosis

Providing domicillary hi-tech antibiotic therapy was a concept first reported in the USA in 1974 [136]. Cystic fibrosis patients requiring frequent and often long

courses of intravenous antibiotic therapy were trained to reconstitute and administer their own antibiotics at home once they had recovered from the acute phase of their infection. The results were promising with no serious complications in 127 courses of therapy.

The success of home parenteral therapy in cystic fibrosis has since been confirmed. Winter *et al* [137] in the UK found no difference between patients treated at home or those treated in hospital. Bosso *et al* [138] gave infusions of aminoglycosides via a portable syringe pump and found outpatient administration to be convenient, safe and to result in considerable cost savings. A prospective controlled trial [24] comparing cystic fibrosis patients matched according to age, sex, pulmonary function and arterial blood gas values, also found no significant difference between patients treated at home with medications delivered in metered dose bags by an independent home care pharmacy and those treated in hospital. Wolter [10] in a prospective randomised trial of 17 patients and 31 admissions in Australia also found that no clinical compromise associated with home therapy but both advantages and disadvantages in terms of quality of life.

Following this were a number of reports from the United Kingdom of home treatment schemes for cystic fibrosis sufferers being set up in London [139], Leeds [140], Manchester [141, 142] [143], Nottingham [144] and Birmingham [145] and Staffordshire [146].

This reflected both the governments push towards a primary care led NHS (2.1.1) and the preference of these patients to remain at home for their therapy. Other reasons were that throughout the late eighties and early nineties it became accepted practice in many, but not all, centres to give a two week maintenance course of intravenous antibiotics every three to four months [140, 147]. This resulted in patients who were not acutely ill spending two months each year in hospital with the associated disruption to their lives and at great cost to the NHS. A bed was not always available at the specified time and in hospital, doses of intravenous drugs are often not administered at the prescribed time intervals and admissions are costly in terms of staff time [140, 147]. There is also the risk of

cross infection with resistant bacterial strains and viruses which are prevalent in the hospital setting [140, 147].

Gilbert *et al* [141] in Leeds reported their experience with a cystic fibrosis liaison sister having an essential role. They used a formal, structured approach to patient selection and training and a variety of intravenous access devices ranging from intermittent injection, peripheral or central lines to a totally implantable intravenous access device. Patients went home on any one of seven drugs with which they would have been treated in the hospital. Many parameters were measured in order to compare hospital with home treatment in the same patients. Home therapy did not appear to be inferior to inpatient treatment. The provision of a team member who regularly monitors stress, compliance and progress in the home as well as providing support to the patient and family was considered to be vital to the safety and effectiveness of home antibiotic therapy.

Similarly the team in Manchester considered the support given by a cystic fibrosis liaison sister when the patient first went home a key part of their home care service [142, 144]. David [144] reported reservations about the use of central lines and implantable infusion devices so all antibiotics were administered peripherally but a more recent article from the same centre states that long lines and implantable IV access devices are commonly used [143]. In Nottingham some cystic fibrosis patients were being provided with an *ad hoc* home care service [139].

The use of elastomeric infusion devices or pumps for cystic fibrosis patients was not reported in the United Kingdom until 1992. Duncan-Skingle *et al* [148] reported that patients had found that home antibiotic therapy was stressful and time consuming and a study had been conducted in 93 patients to determine whether the Intermate® device (Baxter Healthcare), filled aseptically by the hospital pharmacy, could reduce the time and stress involved in intravenous drug administration. The results were favourable as patients were able to perform other tasks or even receive physiotherapy whilst their antibiotics were being

administered. However, there were restrictions as to which antibiotics could be used in the device.

Later the same team reported their first year's experience in a prospective study and concluded that home care using "intermates" had saved 1442 inpatient days and had improved patient's lung function and quality of life [149]. These pumps were in use in other centres such as Leeds [150] and Birmingham [151].

Pharmacists working in Leeds put in a bid to provide the home care service which was being provided by a commercial company [140]. They won the contract from the local Health Authority and reported financial savings of approximately £125,000 (45% reduction) in its first year of operation. Similar conclusions that infusion pumps were less time consuming and tiring for both the patient and carer, especially with the newer programmable pumps where patients were on multiple antibiotics with different schedules, were being reached in the United States [138, 139, 152].

In all the United Kingdom studies the general practitioner had at least partial responsibility for prescribing drug therapy. The agreement of the general practitioner was always sought before the patient went home and care was shared between the primary care and secondary care teams to varying extents. North Staffordshire Hospital won a Pharmaceutical Care award for shared care in 1998 for its multidisciplinary team providing home infusions for cystic fibrosis patient's [146].

Latham [153] discusses the fact that care for cystic fibrosis patients is not provided equitably around the United Kingdom and when a quality service is provided it is dependent on the enthusiasm of an individual clinician to treat the illness. She reports a study of six health regions showing that cystic fibrosis patients were hospitalised at least once a year, for an average of 11 days, with the longest stays for the 0 to 4 and the 15 to 20 age-groups. Another study showed the cost of treating these patients is £10,000 per patient in a specialist centre and the cost of drugs alone in a study in Birmingham in 1989 was £95,000 for inpatient drugs and £216,000 for outpatient drugs for a population of 92 cystic

fibrosis patients. One general practitioner costed the drugs for his one cystic fibrosis patient in London in 1993/94 as being £16,740, 8% of his entire practice budget. Latham suggests a solution would be to share care and cost between the local provider and expert specialist centre so that the local hospital (or general practitioner) does not have to bear the largest financial burden, when extra funding goes to the specialist centre who do less clinically. This was written in the pre-EL(95)5 [41] period and since then some progress has been made in taking responsibility for funding intravenous antibiotics given at home away from the general practitioners.

The Royal College of Physicians published guidance for purchasers on the kind of care they should be arranging for patients with cystic fibrosis. It was prepared by the Cystic Fibrosis Trust in conjunction with the British Paediatric Association and British Thoracic Society and was drawn up by 15 senior consultants [154]. Littlewood [154] explains that in Leeds there is a separate contract for cystic fibrosis patients sub-divided into adults and children and further divided into five lines which are the contract currency. Home care is one of these five lines.

3.1.1.1.2 Other indications for home antibiotic therapy

Following the work of Rucker [136] in 1974, researchers in the United States looked into home treatment for many other infections which required prolonged hospital admission purely for the administration of intravenous antibiotics. These included bone and joint infections, endocarditis, pyelonephritis, pneumonia and soft tissue infections [23, 120, 123, 155-157].

In 1978 Antoniskis et al [156] compared 14 patients treated at home with antibiotics for infective endocarditis or osteomyelitis with seven controls treated conventionally in the hospital. The major concern was the potential hazards of home therapy but the study reassured the researchers that outpatient parenteral antibiotic self-administration was no more dangerous, and no less efficacious, than inpatient nurse-administered parenteral antibiotics providing patient selection and education are appropriate.

Stiver and his team [155] reported the results of treating 23 patients over 12 months for a range of both fungal and bacterial infections. The results were compared to those of matched controls. The patients were visited by a nurse in their homes daily and antibiotics were aseptically prepared by the hospital pharmacy department and delivered to the patient's homes in a frozen state. The same team later described their experience with 95 patients with similar success [120]. Home therapy failed in 10 patients who required subsequent treatment in hospital. Of the remainder of the 102 courses of home therapy the patient returned to school or work in 29 instances, and could not work but resumed social activities in 64 instances.

Kind *et al* [157] studied 15 patients with infective endocarditis and osteomyelitis. These patients returned to the hospital for catheter changes and to pick up new supplies every 48 hours. They were provided with heparin and the antibiotics prepared aseptically in the hospital pharmacy. The intravenous nurse team, based in the pharmacy department, was the first to report a problem with patient compliance with one of the patients finishing her antibiotic course prematurely. As with the previous studies no major problems were reported. The benefits were that the patients could return to their usual way of life and even to work or school and that this method of treating patients was substantially cheaper than conventional methods. The issue of compliance and adherence to protocols by patients was later studied by Boyer [158] and the need to monitor this is now recognised [143].

A larger study was reported by Poretz *et al* [23], 150 patients were treated for osteomyelitis, septic arthritis, pyelonephritis, endocarditis and other infections. Antibiotics used included penicillins, cephalosporins, aminoglycosides, clindamycin, chloramphenicol, vancomycin, piperacillin, moxalactam and ceftriaxone. Antibiotic solutions were prepared in the hospital pharmacy and given to the patient to keep refrigerated until use. The programme was co-ordinated by a hospital pharmacist from the pharmacy with the help of an intravenous nurse. Complications were not serious and occurred infrequently. Patient acceptability was high allowing patients to return to their normal lifestyles and representing a cost saving and more prudent use of acute-care beds.

In an editorial commenting on the work of Poretz, Frame [159] stated that control systems were mandatory and required the involvement of hospital-based pharmacies, intravenous therapy services and 24-hour-a-day availability of medical personnel to ensure the high rates of efficacy reported in the literature

Rehm *et al* [112] reported treating 48 patients with antibiotics at home for conditions such as osteomyelitis, wound infections and endocarditis. The patients were taught to reconstitute and administer mostly β-lactam antibiotics by a pharmacist. By this time subclavian central (Hickman) catheters were being used for patients requiring longer-term treatment to obviate the need for continual replacement of peripheral cannulae. The importance of a multi-disciplinary team being involved in patient selection, education and follow-up was stressed in this study. 49% of patients referred for possible home therapy were rejected after evaluation by the team. These stringent selection criteria were considered vital to the success of the project.

3.1.1.2 Advances in Drug Therapy

Studies treating patients with β-lactam antibiotics found that a four or six hourly dosing schedule put a lot of stress on the patients, was time consuming and resulted in sleep deprivation [152, 160]. The introduction of newer cephalosporins with pharmacokinetic profiles allowing once or twice daily administration in the early eighties meant that the time spent administering antibiotics could be reduced and patients could call into the hospital, or doctor's office or be visited by a community nurse for the daily dose [123]. It was shown that patients could be effectively treated on an outpatient basis attending a clinic or hospital each day for administration of the antibiotic and their introduction was followed by many studies showing that newer cephalosporins could be safely and effectively administered in the home setting [161-164].

Francioli *et al* [126] evaluated the safety and efficacy of ceftriaxone in the treatment of *Streptoccocal* endocarditis in an open, multicentre, non-comparative study. Fifty-nine patients in three European countries were treated with ceftriaxone once a day for four weeks and were followed-up for periods of 4

months to 5 years. No relapses occurred but therapy had to be stopped because of drug allergy in four cases and reversible neutropenia in two. When the condition of the patient permitted and there was adequate care available near to the patient's home patients were discharged from the hospital. It was concluded that this was a safe and efficacious treatment for *streptococcal* endocarditis, was easy to administer and allowed outpatient treatment for carefully evaluated and stabilised patients.

The safety of home intravenous antibiotic therapy for endocarditis patients was questioned by Colford and colleagues [165]. They retrospectively studied the notes of seven patients with blood cultures positive for viridans group *streptococci*, all of whom had been treated with home intravenous antibiotic therapy. Only four of the seven patients successfully completed their course of antibiotics. Therapy was interrupted in two patients because of line-related complications and one patient was readmitted due to recurrent emboli. The authors concluded that until relative safety and efficacy have been assessed in a prospective, randomised, controlled clinical study it was premature to assume that hospitalised and home-based antimicrobial therapy are associated with similar outcomes. Durack *et al* [166] who were embarking on a prospective trial of home therapy for endocarditis commented that these problems were those of home therapy and not specifically of the treatment of endocarditis. Tice *et al* [167] stated that complications such as phlebitis and line infections have been reported as being lower at home than corresponding hospital rates and that these complications may well have been just as likely to happen in a hospitalised patient.

Provision of antibiotic infusions in a frozen form was used by Stiver [155] in 1978. During the mid-eighties commercial home care companies started to provide home antibiotic therapy and partnerships between hospitals and companies were formed. The commercial availability of pre-mixed antibiotics with stability when kept frozen at -20°C for 30 days or more with no loss of activity on thawing for up to 24 hours if refrigerated further expanded the

flexibility in selection of antimicrobial agents and patients eligible for participation in home antibiotic therapy schemes [168].

The choice of antibiotic to use in a home care programme was discussed by Reed [169]. He suggested a formulary of drugs be drawn up and evaluated for use in the relatively uncontrolled home environment. The phamacokinetic parameters of the drug are important as infrequent drug administration allows minimal interference with the patients day to day life, potentially increases compliance and broadens the population of patients who can plausibly be treated with home intravenous antibiotic therapy. Newer longer acting drugs may however increase patient morbidity if compliance is a problem. Pharmaceutical considerations must be taken into account if an antibiotic is to be used in the home environment. Stability data showing the drug to retain potency in the conditions of home, work or school must be considered. Monitoring requirements and toxicity should be taken into account, as problems may not be discovered as quickly if the patient is in the domicillary setting.

Ball [170] was prompted to allow the home administration of teicoplanin for line infections in children with leukaemia by the parents of the children. In order to limit the number of hospital attendances and maintain the children at home for as long as possible indwelling Hickman or Broviac central catheters were used. This allowed the administration of parenteral analgesia and blood products. When a line became infected the patient was admitted to hospital or given teicoplanin during a daily visit to the hospital. The parents felt that they were already familiar with heparinising these lines and felt able to administer the dose of teicoplanin themselves rather than travelling to the hospital each day. Five children received teicoplanin at home and in all five the treatment was effective with symptoms resolving within 2-3 days. No adverse effects were reported. It was concluded that this treatment improved the quality of patients' lives and was cost-effective saving hospital admission costs. Teicoplanin has since been shown to be safe and effective for non-inpatient therapy [171, 172] [173, 174] [175].

3.1.1.3 Advances in Drug Administration

The administration of antibiotics to patients with osteomyelitis via an implantable pump was reported by Perry *et al* [176] in 1986. This novel approach was aimed at increasing local levels of antibiotic at the site of infection, whilst reducing the toxicity associated with high systemic levels of amikacin. The length of hospital stay was decreased as patients could be discharged home with the pump *in situ.*

The innovative use of computerised ambulatory drug pumps (the CADD-VT® manufactured by Pharmacia/Deltec) was reported by Brown *et al* [160]. This method of drug delivery was found, in 38 patients, to permit accurate drug volumes, exact dosing schedules and a reduction in nursing visits. It caused minimum disruption to the patient's lifestyle and allowed four hourly dosing regimens without the need for the patient to wake during the night. Patients who previously could not be considered for home antibiotic therapy because of the lack of skills to self-administer were able to receive home intravenous antibiotic therapy. A peripheral intravenous access device was used for some therapies but the evolution of the long-line or percutaneous central venous catheter gave an alternative to subclavian or Hickman catheter placement in extended antibiotic therapies. Stability of drugs for 24-hour periods at room temperature or above and the need for concentrated solutions of the drugs in 50 or 100mls of diluent created some pharmaceutical challenges. Acceptance by physician and patient was immediate and overwhelming but nursing staff were slow to become comfortable with the equipment.

Others were also able to demonstrate the success of programmable ambulatory infusion devices such as the CADD-VT®, Pharmacia Deltec for the administration of antibiotics in the home environment [114, 177]. Disadvantages included the fact that the patient is continually attached to a pump, that the pump itself is heavy and that the cassette forming the drug reservoir only accommodated 100ml of fluid. Williams *et al* [177] discuss the relative benefits of other pumps available for home therapy. The use of these programmable infusion devices was found to extend the range of patients eligible for home intravenous antibiotics, avoid the use of newer, more expensive antibiotics with

longer half-lives and cost no more than using the intravenous mini-bag system [114] [12].

A large prospective, open-label (unblinded), multicentre trial was reported by the home intravenous antibiotic therapy (HIAT) study group, in 1994 [128]. It highlighted the results of treating a variety of infections on an outpatient basis using cefotaxime and the CADD-PLUS ambulatory, programmable infusion pump (Pharmacia Deltec). A total of 238 patients in five infection categories were enrolled from 10 sites. Of the 211 patients who completed the study 95.3% exhibited a satisfactory or improved clinical response following treatment. It was concluded that the administration of cefotaxime via an ambulatory delivery system to outpatients was a clinically effective treatment of serious infections and may be less expensive than inpatient antibiotic therapy. In addition the patient's quality of life may be improved and loss of income or interruption of education minimised and the risk of nosocomial infections may be reduced. The effectiveness of sub-populations of patients with diabetes mellitus, HIV [26], skin and soft tissue infections [178], patients suffering from pneumonia [179] and patients over 60 years of age [180] were also reported.

Baptista *et al* [8] reported their experience with 211 courses of home intravenous antibiotic therapy. 150 patients were treated including 56 with acquired immunodeficiency syndrome (AIDS). Antiviral, antifungal, antibiotic and antiprotozoal therapies were given in the domicillary setting. Most courses were administered via a central access device ranging from implantable disks and tunnelled temporary catheters to Hickman lines and other central access methods.

Bernstein [181] wrote an update on home intravenous antibiotic therapy in elderly patients. These patients often require longer treatment than comparable disease in younger patients and are much happier in their home environment. Infections often have a less obvious presentation in the elderly and even serious infections, such as sepsis and pneumonia, may not result in noticeable fever or white blood count elevation. The initial refusal of Medicare and Medicaid to pay for home intravenous antibiotic therapy meant that few studies had included the older population. Starting in 1990 the Medicare Catastrophic Coverage Act of

1988 would have covered drugs administered at home [39] but this act was repealed [181]. By 1991, many private insurers did cover home intravenous antibiotic therapy based on criteria established by the individual company.

3.1.1.4 Infusion Centre Model

These advances in administration techniques and in drugs with superior pharmacokinetic profiles led to the infusion centre becoming a model for outpatient antibiotic therapy. Poretz [182] described a separate building where pharmacy, laboratory, physician's offices, examination rooms and finance departments were centralised for efficiency, flexibility and convenience. Each patient was seen by a pharmacist, nurse and doctor who shared data about the patient and offered 24-hour assistance. Costs in the centre ran at between 50 and 60% lower than those in the hospital. Similarly Tice [183] reports the success of his office-based service using a wider range of drugs and reported treating more than 1,200 patients with no serious complications. Gourdeau *et al* [117] reported a slightly different model of providing home intravenous antibiotic therapy through a medical day unit.

3.1.1.5 Standards

Poretz [184] comments that it was nursing staff who were the first to recognise officially the growing importance of home intravenous therapy when the National Intravenous Therapy Association published guidelines for nurses involved with outpatient intravenous drug delivery in 1984. Much later in 1992 the American Medical Association published guidelines for physicians involved in home infusion therapy. It was not until 1993 [185] that the American Society of Hospital Pharmacists drafted guidelines for pharmacists and minimum standards for the provision of home infusions were not published until 1999 [186].

Rich [115] reported that standards both in the form of guidelines from professional organisations and as law in certain States were becoming more common with the most extensive set of standards being those developed by the Joint Commission on the Accreditation of Healthcare Organisations (JCAHO)

[187]. Approximately half of the home intravenous antibiotic therapy programmes in the USA in 1994 were hospital-based with about 2000 hospitals in the home care business. The home care agency was either established as a division of the hospital or an agency was set up as a separate affiliated company. Hospital pharmacies usually provided the pharmaceuticals and equipment, and the nursing staff of the home care division, the care. The other major sources of home intravenous antibiotic therapy were independent home infusion companies and a small number of home intravenous antibiotic therapy programmes run from physicians offices. Rich [115] went on to discuss the roles of the various members of the home care team and suggested that the provision of home care involves a major change in roles for health care providers. He also stated that home intravenous antibiotic therapy would continue to expand so long as adequate reimbursement is available and with the current emphasis on the cost-effectiveness of healthcare from government officials that looked likely.

3.1.1.6 Home Antibiotic Infusions in the United Kingdom

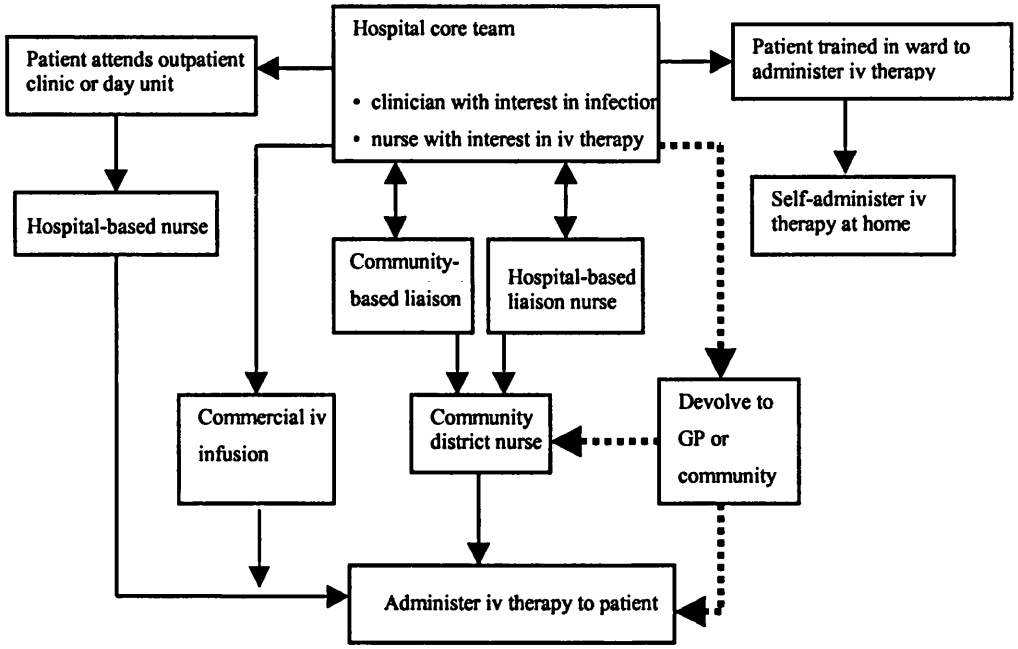
Littlewood [188] reported the findings of a study of the US National Alliance for Infusion Therapy (NAIT) of February 1993. The most common home infusion therapy in the United States was found to be antibiotics followed by enteral nutrition, parenteral nutrition, chemotherapy and analgesics, accounting for 58% of the patients receiving home infusion therapy from the 60% of the home care market surveyed. 38% of these patients were receiving home intravenous antibiotic therapy. Littlewood [188] points out that although the other four categories of home therapy are being developed in the United Kingdom home intravenous antibiotic therapy has been slow to gain acceptance and there seems to be no good reason for this. It can often be administered peripherally rather than by a central line and the drugs and administration cause far fewer complications than TPN or chemotherapy. It is more cost-effective than hospitalisation and although in the United States 70% of patients receiving home intravenous antibiotic therapy use pumps, gravity feed is perfectly safe and the availability of pumps ought not to be a limiting factor. She suggested that the problem of transferring this treatment and associated costs from secondary to primary care and agreeing shared-care protocols and shared budgets for these

patients was one of the obstacles in the path of the development of home intravenous antibiotic therapy in the United Kingdom and asked whether pharmacists ought to be playing a more active role in promoting and developing this service.

Conlon [99]discussed the issue of sharing the care of patients receiving home intravenous antibiotic therapy (2.1.3.7). He reports that in the United Kingdom the drive to develop home intravenous therapies is as much about quality of care and appropriate bed-usage as it is cost and that the aim of home intravenous antibiotic therapy should be "to provide the best treatment for the patient's infection with the least disruption to the patients life while optimising safety and bed usage". The importance of a written protocol was stressed so that all parties were aware of their role. The availability, 24 hours a day, of a help-line for the patient, general practitioner or community nurse to contact the hospital home care team was also considered vital to the success of a home antibiotic service. Monitoring could be shared and the clinical legal and financial responsibilities for the patient should be made clear in the shared care protocol.

Nathwani [189] [40] also discusses outpatient and home antibiotic therapy programmes in the context of shared care. He reported that 76% of GPs saw no advantage to themselves and a substantial disadvantage (70%) in terms of increased workload. However 94% thought that patients would benefit from being treated in their home environment. The current models in the United Kingdom for delivering outpatient and home antibiotic therapy are demonstrated in Figure 3.1. Parker *et al* [190] demonstrated a saving of 532 bed days in a year using non-inpatient intravenous antibiotics but point out that real progress in this area will require better co-operation between hospital and community services.

Figure 3.1 Current Models for Delivering Home IV Antibiotic Therapy



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Nathwani and Davey [37] again questioned the slow emergence of home intravenous antibiotic therapy in Britain and Europe compared to the USA. The authors comment that intravenous antibiotics are used far less frequently in Britain than in the USA and a change in treatment philosophy of serious infection would have to come about before a large increase in home intravenous antibiotic therapy would be seen in Britain. They report the findings of a survey of hospital doctors who stated that obstacles to this model of therapy include reluctance to try something new, lack of good clinical data relevant to the British health infrastructure, practical organisation problems including funding the likely increase in drug costs and concern about reducing the number of available hospital beds. Despite this reluctance there is growing experience of community intravenous antibiotic therapy in Britain for recurrent infections in patients with cystic fibrosis and cancer, chronic orthopaedic infections and for infections complicating AIDS. The problem arises that early discharge of patients does not save the hospital money in the short term as beds are immediately filled with other patients and in fact the cost per patient day may increase. Purchasers and providers need to develop a business plan including home intravenous antibiotic

therapy with realistic short and long-term budgets. Quality assurance standards for these services including the processes of selecting, assessing, training and treating patients as well as monitoring outcome are in place in other countries and should be adopted here. The future of home intravenous antibiotic therapy in Britain depends very much on the shift of funding from secondary to primary care. It was concluded that there ought to be a strategy outlining adequate community support and clear definitions of clinical responsibility between hospital and community services. Their call for a nation-wide NHS strategy for purchasing outpatient intravenous treatment was supported by Conlon *et al* [191].

Kayley reported experience of a home based programme [25] developed through caring for AIDS patients with cytomegalovirus retinitis requiring lifelong foscarnet or ganciclovir. Sixty-seven patients were treated with home antimicrobial therapy for conditions including osteomyelitis, septic arthritis, discitis, vascular graft sepsis, endocarditis, fungal sepsis and cytomegalovirus retinitis with a range of antibiotic, antiviral and antifungal drugs. Depending upon the patient the antibiotics were either self-administered, administered by a partner, a district nurse or a doctor. District nurses were trained to look after these patients and a clear shared-care protocol was written which gave back-up telephone numbers and clearly stated who was responsible for what. The home care team included a consultant in infectious diseases, a community specialist nurse in intravenous therapy, a hospital pharmacist, an infectious diseases senior registrar, clinical microbiologist and clinical nurse specialist in TPN. All patients had a subclavian central venous line. Complications were few and the three line infections reported all occurred in AIDS patients with lines *in situ* for more than six months. The programme resulted in a considerable saving in hospital beds and patient, community nurse and physician satisfaction.

Fay and Evans [192] describe their experience of providing non-inpatient intravenous therapy from a paediatric oncology ward. They note that parents feel that practical involvement gave them a feeling of control and alleviated, rather than added to their anxiety. However it may be too demanding at certain stages of their child's illness.

A consensus statement on outpatient and home parenteral antibiotic therapy (OHPAT) in the United Kingdom was published in 1998 [193]. It stated that OHPAT has low government priority and existing activity is poorly co-ordinated and under-resourced. There have been calls within the NHS for approaches that reduce delays in discharging patients and lessen the need for admitting them in the first place, both of which OHPAT achieves. The consensus statement advises healthcare workers and managers on how best to develop, fund, implement and evaluate a new or existing programme.

An audit to evaluate the effects and treatment outcomes of orthopaedic patients receiving home antibiotics via a PICC line was carried out in Chester [194]. A model was used whereby a nurse specialist placed a PICC line and taught the patients to administer their own antibiotics and supported them at home. The audit consisted of a patient questionnaire, staff questionnaire, and examination of documentation and drug and equipment costs. Patients were satisfied with education and emotional support, staff were easy to contact and problems were dealt with quickly. 86% of nurses were confident in dealing with patients with PICC lines and documentation was 100% complete. 75% of patients had no incidence of line occlusion and 81% had no incidence of line sepsis. There was one incident of mechanical phlebitis.

Newland and Ketley [173] report treating haematological malignancy patients with teicoplanin and ciprofloxacin as non-inpatients instead of their inpatient regimen of gentamicin and piperacillin. They reported favourable outcomes, acceptance by patients and cost savings although highlighted the fact that vacated beds do not remain empty. Non-inpatient treatment increases the efficiency of the unit but does not reduce operating costs. They also noted that issues of payment and medicolegal responsibility need clarifying.

3.1.2 Home Parenteral Nutrition (HPN)

3.1.2.1 History

In a brief history of home parenteral nutrition (HPN) Grundfest and Steiger [195] attribute the idea of providing enough nutritional support intravenously to achieve positive nitrogen balance to Elman in 1948. In 1952, Aubaniac went on to describe the technique of percutaneous subclavian venipuncture and in 1968 Dudrick *et al* proved that hypertonic solutions of dextrose, amino acids vitamins and minerals could be delivered safely and easily through a polyethylene central venous catheter and that such solutions could provide normal growth and positive nitrogen balance while putting the bowel at rest.

Scribner *et al* [116] first described the concept of an artificial gut system for patients incapable of enteric feeding (3.1). In 1973 the same team introduced a right atrial catheter which facilitated self-administration of nutrients and also had a cap which allowed heparinisation to keep the line patent [196]. Experience with 22 catheters placed in 18 patients requiring long-term total or supplemental parenteral nutrition was reported. The development of an indwelling silastic catheter was an important advance. It had a Dracon-cuff and was made of silicone rubber. This had the advantage of allowing TPN to be delivered to high blood flow areas such as the right atrium. The silicone was biologically inert and decreased catheter obstruction and thrombosis. It's pliability allowed it to be left in place for long periods in the right atrium and superior *vena cava* without causing perforation. One catheter had been in place for 15 months but the average life span was 3.9 months. The cuff was placed in a subcutaneous tunnel and growth of fibrous tissue around it acted as a barrier to infection. Broviac and colleagues [196] recommended the use of this catheter in-hospital or at-home for parenteral alimentation that was required for four weeks or longer. It later became known as a Broviac catheter.

In 1978 came the development of the wider bore Hickman catheter which was widely used in home parenteral nutrition (HPN) patients because of it's improved construction durability and dependability [197].

In 1973 a Canadian study [198] reported experience with one patient who was treated for 23 months with HPN via an indwelling silastic catheter. A 36 year old house-wife and mother of three young children was successfully rehabilitated 100 miles away from the centre looking after her. A pneumatic pressure system was used to infuse the nutrients overnight. The patient suffered no episodes of infection. This was attributed to the use of filters as solutions had grown visible organisms and fungus had been cultured from solution remaining in the bag at the end of the infusion period. During a total of 30 months of infusion the silastic catheter was retained with no incidence of reaction or thrombosis.

The same team later reported their experience of treating 12 patients with HPN, surviving 4 months to 5 years [199]. The patients either had massive gastrointestinal loss from vascular injury or inflammatory bowel disease or had chronic intestinal obstruction. Venous access was via Broviac catheters introduced into the superior *vena cava*. The mean survival of these catheters without complication was 15.8 months but in four patients they had lasted for more than 28 months. All but two patients were able to maintain ideal body weight and were socially rehabilitated. Three patients developed catheter infections which were all successfully treated. These were all patients who suffered from continuing abdominal sepsis. These rates of infection were no higher than might have been expected in the hospital setting [200]. It was concluded that quality of life was improved for all of these patients who were able to return to family life and some to work or classes. One even managed to take a holiday across the Atlantic. The alternative for these patients would have been a chronically malnourished state or permanent residence in hospital. Depression was a problem in the two patients who had a history of depression but most patients coped well. Centralised preparation of the nutrients was carried out in the hospital pharmacy and was reported to have many advantages over preparation by the patient. These included freeing up the patient's time, reducing the frequency of visits to the pharmacy, modification of composition without patient re-education and quality control. It was concluded that HPN was safe and required a remarkably simple delivery system but there remained a huge scope for further research into nutritional requirements of such patients.

Fleming *et al* [201] used the same tunnelled catheter to deliver home parenteral nutrition (HPN) in seven patients with extensive Crohn's disease of the small bowel and malnutrition. They successfully provided HPN for a total of 120 patient months. Patient care was co-ordinated through a multidisciplinary HPN team which consisted gastroenterologists, pharmacists, a gastrointestinal surgeon, a social worker, a psychiatrist, a nurse and a business manager. Pharmacists took the leading role in teaching HPN techniques which took on average 2½ weeks in hospital after the insertion of the catheter. In this study the patients were taught aseptic technique and made up the solution themselves. A local pharmacist supplied the necessary nutrients. HPN was not found to reverse or prevent complications of Crohn's disease other than malnutrition. Depression was again noted in some patients. No line infections were seen. After the patients started on HPN the number of hospital admissions was halved when compared to an equal period before HPN. Quality of life for these patients improved with return to more normal lives and pain relief requirements for abdominal pain decreased.

Two years later the same team reported further experience with 23 patients treated with cyclic nocturnal HPN [202]. Average weight gain was 13.6kg. 12 patients had returned to work or school, six were active housewives and the remainder remained disabled by their underlying disease. One death occurred from a hyperosmolar coma, there was one episode of bacteraemia, one of infection at the catheter entry site and 4 displaced and 5 damaged catheters. HPN was concluded to be a safe alternative to prolonged hospitalisation which could dramatically replete the chronically malnourished patient.

In 1978, Strobel *et al* [203] reported treating 34 paediatric patients with HPN. 34 patients, ranging in age from 1½ months to 20½ years, were treated for 23 to 786 days. Solutions were infused over a 10-14 hour period each day via a volumetric pump. They were obtained from and prepared by the hospital pharmacy and refrigerated until used. All patients experienced weight gain sufficient to improve their percentile standing on standard growth charts and, regardless of disease state, all experienced a decrease in symptomatology and improved general state of well-being whilst receiving HPN. Normal lifestyles were encouraged including participation in sporting activities. Infection of the

catheter tip occurred in four instances and sepsis in a further four. In all 22 catheters were removed because of complications, a rate of one per 359 days. It was concluded that HPN is a safe, simple and effective means of maintaining optimal nutrition in paediatric patients with severe digestive tract disorders and that patients and their families benefit psychologically by being at home and resuming relatively normal lives.

Byrne *et al* [204] noted that total published experience with the techniques used for home parenteral nutrition (HPN) was still small and presented data on a further 106 patients. Following this there were many further reports, all of which concluded that HPN, was safe and effective, with low complication rates. A Danish team [205] reported treating 19 patients with long-term parenteral nutrition mostly at home for six to 63 months, Grundfest *et al* [195] treated 43 patients at home for 45 months reporting that obstruction was less of a problem with the wider bore Hickman catheters. Fleming *et al* [206] used Broviac catheters tunnelled subcutaneously down the anterior chest wall in 27 patients and found a difference in complications and life span of the catheter between adolescents and adults and Dudrick *et al* [197] reported their experience of 100 patient years of ambulatory home TPN in 133 patients between May 1974 and December 1983. Average implantable catheter life was 250 days with the longest being in place for eight and a half years. The catheter sepsis rate was once every 2.6 catheter-years.

A questionnaire survey was carried out in the USA during 1979 [207] to establish a baseline of pharmacy involvement in HPN. It was found that the "typical" hospital providing HPN services was a private, non-profit, greater-than-400-bed, university-affiliated teaching hospital. The mean length of existence of the HPN programme was 3 years and majority (67%) of the hospitals were treating 2 or fewer patients. In 57% of the programmes the hospital pharmacy exclusively provided pre-prepared parenteral nutrition solutions to the patients and in 25% the patient or family member prepared the solution at home.

3.1.2.2 The United Kingdom

The first report of HPN being used in the United Kingdom came from Hope Hospital in Manchester in 1980 [208]. Five patients were treated at home for 1½ to 9 months. Four of the patients were able to return to oral alimentation and the fifth was likely to require TPN indefinitely. Broviac catheters were used and the patient was taught to use a constant infusion or overnight gravity infusions. It was commented that HPN was effective and added a new dimension to the treatment of these patients but the place of this expensive form of therapy in a society where health care was being subject to tight cash limits required further evaluation.

Later in the same year a symposium was held on HPN in England and Wales [36]. It was postulated that the reason HPN had not been developed in the United Kingdom to the extent it had in Europe and the USA was due to the absence of the need to pay hospital fees, medical inertia and problems with organisation and funding. A statement of the position regarding HPN was published [36]. Six centres had treated a total of 25 patients with HPN over the previous two years. Most were between 20 and 40 years of age. Crohn's disease was the most common indication for treatment. Seven patients had died but only one death was caused by a complication of the treatment. At the symposium there was general agreement about which patients should be treated and that a subcutaneously tunnelled silastic catheter should be used for administration. There was disagreement as to the necessity of a pump. Catheter-related sepsis was virtually universally lower when the patients were at home than when they were in the hospital. The cost of maintaining these patients at home was high but considerably cheaper than undertaking the same treatment in hospital. The most satisfactory results were those where patients were tided over until their bowel adapted or disease remitted. Following this symposium the United Kingdom HPN register was set up to obtain information on the indications and benefits of HPN so that selection criteria could be developed for it's more efficient use.

A report of the first 200 cases of HPN in the United Kingdom and Ireland from the HPN register was published in 1986 [7]. 28 centres contributed case-reports but 7 centres registered 75% of cases. Most patients were between 10 and 40

years old with the majority of patients suffering from Crohn's disease (90 patients) or mesenteric vascular disease (27). 85 patients required treatment for less than a year and 17 for more than two years. It was found that patients whose indication for HPN was a primary intestinal disease had a better quality of life than those in whom the intestinal failure was secondary to a systemic disorder. There were 34 deaths, 10 due to complications of treatment, but 56 patients managed to return to enteral feeding. The mean incidence of catheter related sepsis was 0.35 episodes per year. This varied from 0.2 to 0.9 depending on the length of experience of the supervising centre and was probably related to experience of the nurses dealing with the patients and their ability to teach catheter manipulation and infusion techniques.

This finding was in line with results of studies from the USA [197, 206] showing that catheter-related sepsis can be reduced through adherence to a strict catheter care protocol and adopting a team approach to parenteral nutrition. Of the 200 patients registered since 1977, 92 were still on treatment. It was noted that many centres rely on commercial firms to supply HPN patients directly with 3 litre bags containing one days supply of nutrients. Most used volumetric pumps to infuse the solution overnight. The authors estimated that about 2 patients per million in the United Kingdom need HPN each year and suggested that if this was the case there would be 100 new registrations each year. It was concluded that although HPN cost about £25,000 per patient per year in the United Kingdom, used discriminately it is cost-effective. The ability to look after a family or work gainfully offsets the cost of HPN to some extent.

The largest centre in the United Kingdom at Hope Hospital in Manchester published a review in 1988 of 100 patient years of HPN in 76 patients [209]. The most common primary disease was Crohn's and the most common post-surgical complication, short bowel syndrome. 40% of patients required HPN for six months or less but one patient had been on treatment for seven years. Catheters used included Broviac (56%), Hickman (13%), Vygon Nutricath catheters for shorter-term cases (28%) and Portacath in 2 patients. The quality of life measured on a four-point scale was good for the majority of patients. 35 went to work full-time and 13 part-time, school children were able to take exams

and four healthy babies were born to three of the women. Three of these pregnancies were reported separately [210]. Sepsis and superior *venal caval* thrombosis were the main problems encountered. The overall mortality rate was 18%. Five deaths could be related to HPN. The sepsis rate was 0.14 episodes per patient per year and the overall complication rate was equivalent to one complication every 3.1 patient years. It was concluded that HPN is an effective and safe treatment of intestinal failure and recommended that dedicated units for providing HPN be established on a regional or supraregional basis.

Puntis [211] drew attention to the importance of training patients and parents prior to discharge from hospital, including adequate psychological preparation together with explanations regarding the indications for nutritional support and instruction in safety and hygiene. He states that some parents will be unable to cope with the technical and emotional demands of HPN, which are far greater than those for home enteral nutrition. HPN has the benefit of possibly preventing the developmental retardation and adverse emotional effects which are otherwise virtually unavoidable consequences of long-term hospitalisation. However in selecting children for HPN he stresses that it is necessary for parents to be highly motivated, have a stable relationship, adequate housing and to be of above average intelligence. In a review of ten children on HPN all parents regarded HPN as infinitely preferable to hospital care. The importance of planning, good training and formalised shared care was echoed by Long [212].

Initially most patients receiving HPN in the US had undergone massive bowel resection for Crohn's disease or mesenteric vascular injury or suffered from severe short bowel syndrome [201, 204]. In 1991 the American Society for Parenteral and Enteral Nutrition (ASPEN) published a report [134] on outcome of home parenteral and enteral nutrition. Cancer was the most common diagnosis requiring such therapy and the percentage of new patients infected with the HIV virus and diagnosed with AIDS who received parenteral nutrition was found to equal the number of new Crohn's patients. Mughal and Irving [7] had reported in 1986 that there appeared to be less emphasis on the treatment of malignant disease with HPN in the United Kingdom than in the United States where malignancy was the indication in a third of those registered. The numbers

of patients with malignant disease and AIDS being treated with home TPN in the UK are increasing [213]. The ASPEN report also stated that most patients on HPN had either no hospital readmissions or one and that related mortality was 3%.

A systematic review of home parenteral nutrition was published in the UK in 1997 [213]. This concluded that the quality and range of evidence of effectiveness was disappointing. The types of patients being treated were well documented as were complications, survival, duration of therapy and reasons for discontinuing treatment, however organisational models had been poorly assessed particularly the contribution of the organisational model to patient outcomes. A need was identified to properly evaluate all changes in delivery management.

Home TPN has become an established therapy in the UK [101, 213].

3.1.2.3 National Standards for HPN

The American Society for Parenteral and Enteral Nutrition (ASPEN) have published standards for home nutrition support the most recent update being in 1999 [214] with the aim of assuring sound and efficient home nutrition support care and assist organisations and health professionals in providing safe and appropriate nutrition care. The standards give examples to ASPEN's multidisciplinary members of implementation of specific standards. After the first version of these standards was published there was a call for standards and structures of service to be defined nationally in the United Kingdom for the 2,300 patients on home enteral nutrition and 210 patients receiving HPN [215]. The question of funding required clarification and the quality of training and support materials needed to be improved [215].

In 1994 a working party of the British Association for Parenteral and Enteral Nutrition (BAPEN) produced standards to guide those responsible for organising

the care of a person who needs parenteral nutrition at home. There had recently been a change in the way HPN was funded, the contract for the provision of nutrient solutions, equipment and all other needs had to be agreed between a Health Authority, acting as purchaser, and a supplier. Included in these standards was the requirement to produce guidance on the contribution and responsibilities of the general practitioner and agree a shared-care protocol, provide adequate training to meet goals laid down in the document and well organised, timely supply of the feed and equipment. The financial clarification came later in the form of EL(95)5 [41].

As experience grows with techniques for central venous access and establishing long term nutritional requirements and more efficient monitoring becomes available, the complications associated with the provision of HPN are decreasing. A comparison of the catheter-related sepsis rates related to home TPN in the studies reviewed here is shown in Table 3.1.

All of these studies have not only contributed to the development of the model of delivering TPN at home but have also contributed to overall knowledge of the nutritional requirements of the human body in the longer term. The aim with the majority of patients who have been treated has been bowel adaptation, inducing remission of the underlying disease or managing fistulae which might otherwise have led to life-threatening sepsis but there are some patients who would have no hope of survival if TPN was withdrawn and the availability of this therapy in their home environment has undoubtedly lead to a quality of life for these patients that was previously impossible to attain [7, 197, 216].

Table 3.1, Comparison of Catheter Sepsis Rates in Published Reports of HPN Programmes

Study	Year	Institution	No of pts in study	Catheter sepsis rate	Deaths from sepsis/ Total deaths related to HPN
[28]	1994	Hope Hospital, Manchester, United Kingdom	50	13 episodes of bacterial catheter sepsis, 10 episodes of exit-site sepsis 1 septic-complication per 113 patient months of HPN 0.12 episodes per year of treatment	Not reported.
[209]	1988	Hope Hospital, Manchester, United Kingdom	76	0.14 episodes per patient per year	1 sepsis 5 related to HPN
[7]	1986	United Kingdom and Ireland register of HPN, Hope Hospital, Manchester	200	0.35 episodes per year of treatment, (range 0.2-0.9)	unknown sepsis 10 related to complications of treatment
[197]	1984	St Luke's Episcopal Hospital, University of Texas, USA	133	0.38 episodes per year for implanted catheters (4 patients sustained 24 of the 33 episodes) and 0.33episodes per year for temporary catheters	0 sepsis No deaths reported
[208]	1980	Hope Hospital, Manchester, United Kingdom .	5	septicaemia occurred in 2 patients during the course of the 18 month study but when they were inpatients.	0 sepsis No deaths occurred

Study	Year	Institution	No of pts in study	Catheter sepsis rate	Deaths from sepsis/ Total deaths related to HPN
[195]	1980	Cleveland Clinic Foundation, Cleveland, Ohio, USA.	43	Unknown. Most frequent reason for catheter removal was suspected sepsis	Unknown. 1 patient died from iatrogenic causes
[206]	1980	Mayo Clinic, Mayo Foundation, Rochester, Minnesota, USA.	27	6 episodes of septicaemia in 5 patients 0.11 episodes per year on HPN	0 sepsis 0 due to HPN
[36]	1980	6 United Kingdom centres	25	unknown but less when patient at home than when in hospital	1 sepsis 1 due to HPN
[204]	1979	UCLA Centre for Health Sciences, Los Angeles, USA.	106	18 episodes in 12 patients 0.27 per year on HPN	0 sepsis 0 due to HPN
[202]	1979	Mayo Clinic, Mayo Foundation, Rochester, Minnesota, USA.	23	1 episode of bacteraemia in 34.17 years of patient use 0.03 per year on HPN	0 sepsis 1 HPN
[205]	1978	Rigshospitalet, 2100 Copenhagen, Denmark	19	0.6 episodes per year on HPN	1 sepsis 2 due to HPN
[203]	1978	UCLA Medical School, Los Angeles, California, USA.	34	0.22 episodes per year on HPN	0 sepsis No deaths reported
[201]	1977	Mayo Clinic, Mayo Foundation, Rochester, Minnesota, USA.	7	0 in 10 patient years on HPN	0 sepsis No deaths reported
[199]	1976	Toronto University & Toronto General Hospital, Ontario, Canada & Veteran Administration Hospital, Albany, NY, USA.	12	0.16 episodes per year on HPN	0 sepsis No deaths reported

3.1.3 Home chemotherapy

Traditionally cytotoxic chemotherapy has been delivered as intermittent bolus doses to achieve the highest possible levels of those drugs that the patient could tolerate to produce the maximum chance of significantly reducing the tumour burden and then allow recovery of haematological and immunological function. This has been successful in treating various cancers and very high doses have been shown to overcome resistance to a particular drug. Rescue techniques have also been developed so that a patient may be given a potentially lethal dose of a cytotoxic agent and be rescued with an autologous bone marrow transplant [217]. Most cytotoxic agents work by interfering with the process of cell replication but unfortunately they are not specific for cancer cells and have a narrow therapeutic index [218-220].

Attempts to improve the efficacy and side-effect profile of chemotherapy regimes led to the concept of infusional chemotherapy, the rationale being that, at any one time, for the majority of tumours only about 5% of the cells are in cell-cycle and therefore affected by the chemotherapeutic drug. The doubling rate for most common tumours is measured in months whereas the half-life for most cytotoxic drugs can be measured in minutes or hours. The idea therefore was to expose the tumour to the drug throughout its doubling phase and therefore expose all the cells to the cytotoxic drug. It was the tumours that had a rapid doubling time that responded best to traditional bolus chemotherapy, the postulated reason being that more cells were in the cell-cycle phase and exposed to the drug when it was administered [221].

There have been few prospective controlled trials comparing continuous chemotherapy with the traditional models. Continuous infusions have been shown to reduce toxicity associated with the peak levels reached with bolus dosing schedules [219, 222, 223] and permit a larger cumulative dose to be administered. However, some side effects such as hand-foot syndrome with 5-fluorouracil (5-FU) are increased when the drug is administered by continuous

infusion [218] and one Dutch study [224] found that when vindesine was administered at low doses for 21 days it did not have a more favourable dose toxicity ratio, in fact it caused severe neurotoxicity. This was in contrast to the results of earlier studies [225]. It has been shown in some cases that continuous infusional chemotherapy does induce objective tumour regression but there is little evidence to show that this is superior to traditional regimens [217].

Seifert *et al* [219] compared continuously infused 5-FU with bolus injection in patients with colorectal adenocarcinoma and found the continuous infusion to be superior, most strikingly because of the lack of myelotoxicity in those treated with continuous infusions. Stomatitis was found to be the dose-limiting factor in the continuously infused group. Lokich *et al* [223] reported their experience of 50 trials of home. Gastrointestinal toxicity was virtually eliminated for all five drugs used, alopecia was not observed at all in 3 out of 5 patients treated with adriamycin but hand-foot syndrome was observed with 5-FU. It was concluded that constant infusion cancer chemotherapy was feasible, reliable and safe. Legha *et al* [222] reported a reduction in the cardiotoxicity of doxorubicin when administered as a continuous infusion. A control group treated with a standard regimen in hospital were prospectively compared with a treatment group who had doxorubicin administered as a continuous infusion via a portable infusion pump as an outpatient. 14 of the 30 patients in the control group showed severe changes in biopsy specimens precluding further doxorubicin administration compared to 2 of the 21 patients receiving the drug by continuous infusion. Antitumour activity was not compromised.

Coates *et al* [226] compared quality of life in two groups of patients receiving chemotherapy for advanced breast cancer. Continuous chemotherapy was found to be associated with a better quality of life than intermittent chemotherapy with similar efficacy.

Recent advances in technology such as advances in maintaining central venous access with catheters [196] or implantable systems [227], the availability of small, lightweight, accurate, infusion pumps and better assay techniques to

evaluate stability have facilitated using regimens at home that could previously not be achieved.

There are few established regimens that use only one drug and there is some concern that resistance might develop to these drugs if they are continuously present in low concentrations. The possible use of pulses of high doses has been suggested to overcome this [217].

The EFC regimen of three-weekly inpatient therapy with epirubicin and cisplatin and continuous ambulatory infusion of 5-FU has been reported as being so astonishingly efficacious in a variety of solid tumours, including those of the stomach, oesophagus, breast and ovary that home infusion therapy may be established as a mainstay treatment rather than a novelty for enthusiasts [219, 228]. A multicentre study in the United Kingdom [229] has added further support to this. Overall response rate was found to be 45% in the ECF group compared to 21% with a standard regimen (5-FU, doxorubicin and methotrexate (FAMTX)). Median survival was 8.9 months with ECF and 5.7 months with FAMTX. The authors recognised that the routine use of palliative chemotherapy in advanced gastric cancer is controversial. This view was supported by Abang [230] studying chemotherapy versus best support care for advanced non-small-cell lung cancer. A Medical Research Council trial is now going ahead to study the use of the ECF regimen to shrink the tumour before surgery in patients with less advanced gastric cancer.

An advantage to continuous ambulatory chemotherapy is that patients are able to remain in the familiar environment of their own home rather than spending days in hospital receiving chemotherapy and then recovering from the devastating side effects. Family members often feel useless and unable to help but they can take an active role in care and the patients themselves can feel more in control administering their own chemotherapy [231, 232]. Familiarity with techniques in handling and manipulating drugs as well as knowing and understanding what problems may arise and knowing how to cope with them takes away much of the mystique surrounding this particular group of drugs. The familiar environment of the home setting and support of family and friends may also lead to a greater

sense of well-being, an improved tolerance to drug-related side-effects and an overall improved quality of life [134].

Sewell *et al* [233] described a programme in the United Kingdom where continuous infusions of chemotherapy were administered via a subclavian line to outpatients over days or weeks. Accurate and reliable infusion delivery was achieved by using portable infusion pumps. Pre-filled syringes were supplied to the patient from the hospital pharmacy and a team approach was taken to patient care. The ward pharmacist carried out training and the patients were taught in advance how to deal with problems that may arise. More than 250 patients had received outpatient continuous cytotoxic infusions and it was concluded that if numbers were to increase further the co-operation and involvement of both hospital and community-based healthcare professionals would be necessary.

The same team reported the continued success of the HOPE (Home Oncology Programme, Exeter) in 1989 [127]. More than 350 patients were treated at home using a portable pump. with few difficulties and excellent patient acceptability. Patients with solid tumours of the breast, colon, oesophagus, pancreas and other sites, often with metastatic disease were considered for treatment in the HOPE programme. The catheter sepsis rate was less than 1% and the incidence of other adverse effects low.

A prospective randomised trial comparing inpatient with outpatient continuous infusional chemotherapy in patients with locally advanced head and neck cancer was reported by Vokes *et al* [234]. Patients chose to be inpatients or outpatients and crossed-over to the alternate delivery method for the second cycle. 11 patients were treated as outpatients and 8 chose to stay in the hospital. The patients who received 5-FU as outpatients reported that it was convenient and effective and all chose it again. No significant difference between the frequency or severity of side-effects was found. It was again concluded continuous infusion outpatient chemotherapy was a viable alternative to in-hospital administration.

A consultant oncologist advocated links between hospital oncology departments and general practice. He reported three patients who were receiving chemotherapy at home [235]. The drugs were given either by the patient's general practitioner or by a specially trained practice nurse. General practitioners had not been reluctant to take on the administration of home chemotherapy but some had been reluctant to take on the cost.

A study to determine the quality of life of patients receiving low dose ambulatory chemotherapy and to identify areas where patients may need further help or advice was conducted in Exeter [236]. A questionnaire was designed, piloted and finalised using patient feedback. A researcher interviewed the patients during their fortnightly visit to the outpatient clinic. Results from the pilot (14 patients) showed that 50% felt anxious and depressed and 93% stated how important their visits to the oncology outpatient clinic were. Giving up work was a particular problem for the male patients interviewed. Only 3 patients were aware of their ambulatory pump and six were worried about damaging the pump. 70% of patients interviewed had either lost or gained weight and 79% said they no longer felt sexually attractive. Few problems were reported with the chemotherapy. This tool could also be used for comparisons of the quality of life of patients receiving traditional chemotherapy regimes in the hospital with patients receiving infusional chemotherapy at home.

Vasey and Steward [220] look at how GPs can improve the quality of life of patients receiving palliative chemotherapy. They note that the availability of small portable electric pumps has made it possible to treat these patients at home. The general practitioners role in shared care of these patients includes good communication with the hospital or cancer centre, monitoring between courses of chemotherapy or hospital visits, looking for the first signs of infection, monitoring pain and well-being, prescribing appropriate opioids, antidepressants and other medication and taking blood samples to cut down on the frequency of visits to the hospital. The general practitioner or district nurse may also be involved in helping the patient with the care of an indwelling central line to prevent infection or blockage.

A prospective, controlled evaluation of home chemotherapy in children with cancer was reported by Close *et al* in 1995 [237]. Quality of life, billed medical charges and out-of-pocket expenses were compared when chemotherapy was given in hospital or at home. The first two courses of chemotherapy were given in the hospital and if suitable further courses were given at home. Quality of life was measured using a parent-scored Likert scale. Consumption of supplies and hours of professional's time were measured in an unsuccessful attempt to relate costs to charges. 76 courses of home chemotherapy were administered avoiding 312 days of hospitalisation. Charges for home chemotherapy were 17% less than for inpatient chemotherapy. Although this reduction was less than expected, home care was found to be far less disruptive to family life and quality of life was better at home.

Provision of a home chemotherapy service involves considerations which may not apply to other forms of home infusional therapy [134]. The importance of handling of cytotoxic drugs and disposal of waste must be stressed to the patients, families and anyone else involved. The patient and their relatives should be considered at risk to accidental exposure and cytotoxic waste may be excreted in the patients' urine and faeces. Extravasation is more of a problem with this very toxic group of drugs and toxicities may be more severe and dehabilitating than with other home therapy. Chemotherapeutic agents should be made up in the doses required for infusion aseptically in a designated area of a pharmacy to minimise exposure to the drug, the risk of microbial contamination and the risk of an incorrect dose being administered.

The literature suggests that home continuous chemotherapy infusions with the potential for greater risk [134] have been more widely accepted in the UK [127, 130, 228, 233, 235, 238] than the relatively lower risk home antibiotic infusions [37, 193].

3.1.4 Home Opioid Infusions

Home infusions of opioids for the terminally ill have a well-established place in the clinical management of terminal disease where the primary concern becomes the quality of the patient's remaining life. Various methods are available for pain control in these patients and include oral medication, transdermal opioid, intermittent injections, continuous infusions, epidural blocks, transcutaneous electrical nerve stimulation (TENS) and neurosurgical procedures. Pain is very patient specific as is pain relief. A drug, route and method of administration must be chosen that is effective and best suits the patient's needs. When continuous opioid infusions are used they are most commonly administered by the subcutaneous route and most district nurses in the United Kingdom are very familiar with syringe drivers.

For some patients the subcutaneous or intramuscular route may not be the best choice due to lack of cutaneous tissue or coagulopathy may led to severe bruising after intramuscular or subcutaneous injection. Intravenous infusions of opioids have been shown to be very effective for pain relief following surgery [134] and for terminal illness [132, 239] and with the development of pumps, patient controlled analgesia (PCA) has become widely used both in the inpatient and home care settings [240]. There is no reason why patients who are terminally ill or recovering from surgery cannot be treated in the domicillary setting with intravenous opioid infusions, providing that this is their only reason for staying in hospital. Reports of home intravenous opioid infusions are few but whether this is a reflection of the extent to which it is used is not known.

Fraser [239] reviewed the literature of the experience with continuous intravenous infusions of morphine reporting that experience has been favourable to date. He stated that intravenous infusions could provide uniform pain control by avoiding fluctuations and that the total daily dose of morphine that the patient receives may actually decrease. Caution was advised due to the potential for accidental overdose or suicide. This could be a problem if the patient was treated at home, however newer pumps have sophisticated lock-out devices. Miser *et al* [132] found continuous intravenous morphine infusions to be both safe and

efficacious in the control of severe pain, regardless of the cause, in eight children with terminal malignancy. Side effects were common but mild and easily controlled. Adams *et al* [241] and Citron *et al* [131] report the use of intravenous morphine for severe cancer pain, finding it to be a safe, effective means of relieving pain, even in patients with borderline pulmonary status[131].

In 1988, Kerr *et al* [240] treated patients with chronic cancer pain at home with patient-controlled analgesia (PCA). 18 patients with poorly controlled cancer pain or significant side effects from regular administration of various narcotics were taught how to use a portable pump capable of delivering a continuous narcotic infusion with bolus capabilities. Patients received the drug intravenously or subcutaneously. Pain control was good and side effects acceptable. There were significant lifestyle improvements in several patients. One returned to work and three were able to travel outside the country with good pain control. Five patients were able to die at home with family support. It was concluded that this was a highly acceptable and safe method of controlling chronic cancer pain in an outpatient setting and that large doses of narcotics could be administered on an outpatient basis without significant problems.

A United Kingdom study [242] reported treating children with cancer at home. A home terminal care team worked with the patient's general practitioner and family to allow the patients to stay at home and to die at home with their family in a familiar environment. 12 patients died at home and received all the drug therapy that would have been administered had they been in hospital. Three patients had a central catheter inserted for administration of diamorphine and/or blood products and one patient received parenteral antibiotics at home. Care was shared between the staff at the specialist centre and the general practitioner, some choosing to become more involved than others. Hain and Goldman [243] advocate a similar model.

Local spinal administration of medication through epidurally or intrathecally inserted catheters and an indwelling infusion pump was reported by Müller *et al* [244] in 1988 to produce a considerably better efficacy and lower side effect incidence than conventional medication routes. If the catheter was inserted in the

epidural space the dose required was about one eighth of the systemic dose whereas by the intrathecal route only one thirty-sixth of the systemic dose was required. 63 tumour-pain patients had been successfully treated using a continuous infusion through an implanted or external pump either intrathecally or epidurally. It was concluded that many of the patients treated would have had to undergo lengthy or perhaps even life-long treatment as inpatients but this treatment enabled most of the patients to be discharged to their own homes for continuing treatment with the pump systems.

3.1.5 Other home therapy

3.1.5.1 Haemophiliacs

Some of the very first patients to be treated with home infusional therapy were haemophiliacs. In 1970, Rabiner *et al* [245] reported a programme of training relatives of haemophiliac patients deficient in antihaemophilic factor to administer concentrate of the factor intravenously at home after telephone consultation with the physician. Consumption of antihaemophilic factor increased during the study. This was thought to be due to the greater willingness of the patients to report haemorrhages. The number of school or work days lost decreased when patients were admitted to the programme and it was postulated that in the long term there would be lower morbidity in terms of permanent joint damage as prompt treatment of joint haemorrhages would reduce trauma and delay onset of chronic arthropathy. Patients and their relatives were enthusiastic about the programme because of the time saved, rapid relief of pain and the opportunity of helping the patient within the family unit. It was concluded that the benefits of home therapy outweighed the theoretical risks.

In 1972, the same team reported three years experience with the home care programme with 36 patients [246]. Minimal technical problems had occurred but no serious transfusion reactions. The number of reported haemorrhages increased but the number of hospital admissions decreased. The incidence of severe orthopaedic problems decreased as did days lost from school or work. The psychological impact on the families was considered to be of equal

importance providing them with a sense of self-reliance, an increase in mobility and freedom from fear.

Another team working in Massachusetts came to the same conclusion [247]. They formally instructed 45 patients with haemophilia A and B in the management of their bleeding problems. Home infusion was permitted without prior consultation with a physician. Data from the study period was compared with data from the previous year. There was a 74% reduction in absenteeism, 89% reduction in days hospitalised, 76% reduction in outpatient visits and 45% reduction in healthcare costs. No patient had morbidity attributable to this programme, although one relative was exposed to hepatitis from contaminated needles. There was a trend to more normal life patterns and six families took vacations away from home for the first time since the haemophilic member had been born. A study of long term effects on orthopaedic problems was called for but it was concluded that self-therapy would seem to merit trials in the health care delivery of other chronic illnesses.

Similar success has been reported by teams in the UK [248, 249].

Recombinant factor VIII has since been developed with the advantage of a much lower risk of virus transmission. Many haemophiliac patients in recent years have died of AIDS because they were given contaminated factor VIII before the HIV virus was identified. In the United Kingdom products produced using recombinant technology are classified as drugs rather than blood products and pharmacy departments will be responsible for these products and possibly co-ordinating home care arrangements.

3.1.5.2 AIDS

Pizzo *et al* [129] reported treating children with symptomatic HIV infection with continuous intravenous infusions of zidovudine (AZT). The rationale behind this was to produce concentrations of zidovudine (AZT) in plasma and cerebrospinal fluid that would provide constant inhibition of the replication of HIV. A portable programmable infusion pump was used to administer the drug. Children as

young as one year of age were able to carry the device with no impediment to their daily activities. Bone marrow suppression was the only evidence of toxicity that occurred. Improvement of neurodevelopment abnormalities occurred in all 13 children who had presented with encephalopathy before treatment. Most patients had increased appetite and weight gain, decreased lymphadenopathy, hepatosplenomegaly and immunoglobulin levels and increased numbers of CD4 cells. It was concluded that a continuous infusion of AZT was beneficial in children with symptomatic HIV infection, especially those with encephalopathy.

3.1.5.3 Obstetrics

The use of home infusions in high-risk obstetric patients was reviewed by Romeo and Jones in 1994 [250]. The first indication in obstetrics was for women at risk of giving birth prematurely but more recently infusional therapy at home had expanded for this group of patients to include hydration, TPN, heparin infusions, terbutaline administration and antibiotic therapy.

3.1.5.4 Anti-spasmodics

In section 3.1.4 the administration of opiates intrathecally via an implantable pump was described. The same technique has been used to administer baclofen, an antispasmodic, to patients in the domicillary setting. Müller *et al* [244] report that intrathecal administration of baclofen controls even the most severe and hitherto untreatable forms of spasticity and resultant pain. Local spinal action diminishes the undesired cerebral side effects. The 47 patients treated all had an implantable multi-dose pump inserted as therapy was likely to be long-term. Of the patients treated in this study therapy was judged to have achieved results which were excellent in 54%, good in 35%, moderate in 11% and poor in 0%. A multicentre study involving 35 German centres into the long-term effects of such therapy was planned.

3.1.5.5 Other

Experience with treating patients with home infusions continues to expand and it has become accepted practice in many areas to administer infusions of insulin for

diabetes [251], apomorphine for Parkinson's disease [11], desferrioxamine for thallassaemia, algluterase for Gaucher's disease [111], terbutaline and aminophylline for brittle asthma/COPD [252], immunoglobulins [9, 253] [254] and insulin infusions for diabetes [255] in the home setting. In the United States even such complex therapies as vasopressin for gastrointestinal bleeding [256] and inotropic therapies [257] are administered in the home care setting.

3.1.6 The Pharmacist's Role In Hi-Tech Health Care At Home

Pharmacists have been widely reported in the literature to have played an important role in the setting-up and running of hi-tech heath care at home schemes.

In 1979, Kind *et al* [157] first reported a home antibiotic scheme which was run from the hospital pharmacy department with a pharmacy-based intravenous nurse team and a centralised intravenous admixture service. The patients attended the pharmacy every 48 hours to pick up supplies, have their catheter changed and sort out any problems. They saw a physician once a week.

Gaffron *et al* [258] reported the organisation and operation of a home parenteral nutrition programme. The patients were managed by a multi-speciality team, the pharmacist being the person with whom the patients had most contact during their two-week training period. In addition to education the pharmacist was responsible for co-ordinating the transition to home care, offered in-service education on home parenteral nutrition to nurses and house officers, tested and evaluated equipment, co-authored the training manual and edited the quarterly newsletter to patients who were on home parenteral nutrition.

Similar pharmacist involvement was reported by Swenson [259]. In this study the clinical pharmacist was responsible for patient selection, training of patients and their families and co-ordinating the home care team. The paper concluded that a non-distributive pharmacist function had been identified that produced substantial health care cost containment and that insurance carriers needed to

recognise the value of a pharmacist's knowledge and be willing to pay for that knowledge as a separate commodity.

Many studies stress the importance of a multidisciplinary team in the care of patients receiving home infusional therapy [112, 115, 258].

A survey of hospital-based home health care agencies undertaken by Galt *et al* [260] determined the types of pharmaceutical services being provided, the extent to which they were being provided and which pharmaceutical services were perceived as being important. They found that although 85% of home care agencies used the services of a pharmacist, less than 4% actually employed a pharmacist on their staff. The directors of the health care agencies viewed educational programmes, drug regimen review and drug information services the most important functions of pharmacists in health care agencies.

McAllister [261] reported that the evolution of home health care to encompass complicated home infusion services had created new responsibilities for hospital pharmacists. In his introduction to a 13 part series designed to acquaint the hospital pharmacist with home care McAllister [262] states that actively participating in the provision of home health care allows the pharmacist to contribute in an important way to the hospital's viability in the new economic and competitive environments. Assisting in screening, selection, education and training, and clinical monitoring of home health care patients increases opportunities for interaction with patients and adding a home care service may enable the pharmacy manager to increase employee productivity and use resources more efficiently by assuming additional work load. Pharmacists must also become sensitive to psychosocial factors associated with home care and prepare patients and their families for their new lifestyle.

Zilz [263] went on to look at trends in home health care and concluded that the hospital pharmacy department could become even more valuable to the institution and that successful planning of home health care programmes and other alternate modalities should enable the pharmacist to contribute more

substantially to the financial well-being of the institution as well as contribute to better patient care.

Schneider [264] reported that pharmacists were developing training programmes for patients about to be discharged and providing outpatient support services, some where developing entire home care programmes for the care of patients with haemophilia, chemotherapy, hyperalimentation and administration of parenteral steroids and antibiotics. He describes how a pharmacist can develop and implement a home antibiotic programme starting with evaluating the market potential and cost feasibility, then running a pilot project and suggests that joint ventures with vendors or other hospitals may be a way to provide a home care service without making a major commitment of resources from the hospital.

The role of the community pharmacist in monitoring chronic outpatient infections has been discussed by Ackerman and Wolfe [265] and New *et al* [114]. They noted the increasing shift of management of acute illness to community practitioners and the expansion of community pharmacy into home health care. Community pharmacists were reported to be gaining experience in areas traditionally the domain of their hospital colleagues, such as in clinical pharmacokinetics, total parenteral nutrition, intravenous infusion systems, intravenous catheters and parenteral antibiotics. Expertise in therapeutic monitoring of chronic disease states and dose adjustment of medication based upon analysis of blood concentrations was being performed by pharmacists in the community.

A working party report published, by the Community Pharmacy Subcommittee and Council of the Royal Pharmaceutical Society of Great Britain [238] concluded that, in the case of continuous infusions of cytotoxic chemotherapy, monitoring could be conducted by General Practitioners (GPs) and there was a role for community pharmacists involving the provision of infusion pumps and associated medication.

Monk-Tutor [266] reported that home infusion services provided by pharmacists consisted of drug compounding and delivery, patient education and training and

follow-up care including clinical management and monitoring of prescribed drugs and fluid therapies. Despite a growth in the home care market a steady decrease in the provision of home infusion services by hospital pharmacies was reported. In 1985, 40% of hospital pharmacy departments in the USA were providing home infusion therapy services but by 1987 that was down to 29% and by 1989 it was only 17%. An ASHP survey of hospital-based pharmaceutical services [267] in 1994 found that 27% of respondents to their questionnaire offered home infusion therapy services. A study published in 1994 [115] contradicted this stating that "approximately half of the home intravenous antibiotic therapy programmes today are hospital based". A questionnaire survey was carried out [266] to identify pharmacist activities related to these services and reasons for their discontinuation. It was found that many of the hospitals that had ceased to provide home infusion services had done so due to lack of resources including personnel, space and money.

Rich [115] reported that a well co-ordinated team of pharmacists, physicians, nurses and other health care professionals was at the heart of a successful programme for home infusion therapy. Besides the traditional role, the pharmacist was usually responsible for the proper cleaning, maintenance and initial programming of the infusion pump, disposal of hazardous waste products and quality control. Most importantly the pharmacist was responsible for assessing the patient's goals for drug therapy, monitoring the patient for development of drug-related problems and keeping abreast of the patient's progress. The pharmacist was also the source for professional education and drug information for other members of the health care team as well as for patients.

Steel *et al* [268] reported an English project where care for AIDS patients with cytomegalovirus retinitis was shared between the hospital consultant and local general practitioner. This increased communication between primary and secondary care and improved patient care. Both the hospital and community pharmacist played important roles in the care of the patient. The community pharmacist was able to monitor the prescriptions and intervene based on laboratory test results and money was saved by not making up unnecessary

infusions when there had been a change in the patient's condition or circumstances. The hospital pharmacy appointed a pharmacist to co-ordinate the home infusion service and support community pharmacists in providing care to HIV infected patients. Other centres have also reported employing a dedicated home infusion pharmacist [269] with responsibility for co-ordinating the patients care in their home from start to finish: - developing and managing the home care service, patient selection, training, provision of all equipment, meeting service specifications and monitoring the patients in their homes.

Describing some of the pitfalls of home infusional therapy Goldenburg [113] pointed out that the legal accountability of each member of the home care team is unknown but it is crucial that pharmacists, physicians and nurses remain active in the selection process to ensure adequate instruction, safe and effective outpatient treatment regimens and minimisation of medical and legal risks. Prescription management requires the diligent involvement of both physicians and clinical pharmacists. He concludes that multidisciplinary surveillance by pharmacist, physician and nurse will provide optimal care and satisfactory co-ordination of patient and programme needs. The exclusion of any one of these professions will preclude the successful maintenance of an outpatient parenteral programme. This is the message still coming through in more recent literature [193].

In 1993 the American Society of Hospital Pharmacists (ASHP) published comprehensive guidelines on the pharmacist's role in home care [185], these were updated in 2000 [270]. They applied to pharmacists providing home care in all settings including hospital, community, home health agencies and specialised home infusion companies and noted that when different aspects of home care are provided by different organisations pharmacists have a professional responsibility to ensure that all patient care responsibilities are defined, understood, agreed upon and documented in advance. These guidelines [270] state that pharmacists should be active participants in performance improvement activities, monitoring patient satisfaction and outcomes and list some examples of aspects of care that should be monitored.

The role of the pharmacist in ensuring high quality, effective care to patients receiving infusions in the home care setting has been highlighted. Benchmarking services against those of others to assure service level agreements are met and standards of patient care and clinical outcomes are the best achievable is another role in which pharmacists have become very involved in the United States [271-273] and is further discussed in Chapter 4.

3.2 Hi-tech Health Care At Home Surveys

3.2.1 Aims

To establish the current position in England on the purchasing and provision of HTHH under EL(95)5 [41].

To evaluate the effectiveness of EL(95)5 [41] in the delivery of HTHH to patients with an emphasis on the role of the pharmacist.

3.2.2 Objectives

3.2.2.1 Health Authority Survey

Questionnaire survey of the 100 HAs in England to establish

a) to what extent patients are being treated in their homes with hi-tech therapies
b) whether there are geographical or demographic trends in the provision of HTHH in England
c) expenditure on HTHH
d) who is currently providing the various aspects of care for patients being treated at home with hi-tech therapies
e) what contracting arrangements have been made for providing HTHH
f) which aspects of HTHH have been successful/unsuccessful.

3.2.2.2 Trust Survey

Questionnaire survey of Trusts in England to establish

a) how many Trusts are providing home infusions and for how many patients
b) who is providing drugs, supplies and nursing care
c) if there are any audit systems in place to measure quality of care received by these patients and patient outcomes
d) the role of the pharmacist in the provision and monitoring of HTHH
e) in which patients home infusions have worked best and why
f) what have been the barriers to providing HTHH.

3.2.2.3 Commercial Home Care Company Survey

Questionnaire survey of commercial home care companies in England to establish

a) the number of home infusions being provided
b) for which indications home infusions are being provided by commercial home care companies
c) whether they are subcontracting for any of the services they provide
d) who is responsible for setting service specifications for their contracts
e) who is responsible for auditing the quality of care received by patients and patient outcomes.

3.2.2.4 Combining the Results of the Surveys

From synthesis of the data obtained from these three surveys determine

a) whether the information received from HAs correlates with information received from Trusts and commercial home care companies
b) who is responsible for measuring quality of care and patient outcomes for patients receiving HTHH
c) geographical and demographic trends in the provision of HTHH in England
d) and gain a greater understanding of the current arrangements for purchasing hi-tech health care for patients being treated at home in England.

3.2.3 Methods

3.2.3.1 Literature Review

A detailed, fully referenced literature review 3.1 was prepared as described in Section 2.2.4.1.

3.2.3.2 Establishing The Current Position

The initial objective of the project was to establish the current position in England on HTHH and to determine the level of involvement of pharmacists. It was established from the literature review and experience of local health care providers that there were three major groups involved with the purchasing, provision, contracting and co-ordination of HTHH.

3.2.3.2.1 Health Authorities

The first of these was the HAs who are the main purchasers of HTHH in England and have the responsibility for contracting and strategic planning for these patients as laid down by EL(95)5 [41].

3.2.3.2.2 NHS Trusts

The second were the NHS Trusts who function as both purchasers and providers of HTHH. They are often given responsibility by the HA for purchasing HTHH but may also submit a tender to the HA to provide the package of care to patients receiving home infusions under EL(95)5 [41], usually through their pharmacy departments.

3.2.3.2.3 Commercial Home Care Companies

The third major player in the home care market were the commercial home care companies who in recent years in Britain, much as they have done in the United States have become important providers of HTHH. The range, level and extent of services offered vary from company to company. It was felt that the inclusion of information from the commercial sector was vital to achieving a global picture of the present home care market in England.

3.2.3.3 Questionnaire Design

As this questionnaire formed the second part of the Health Authority survey described in Chapter 2, design of the questionnaire is described in section 2.2.4.4.1.

3.2.3.3.1 Development of the Questionnaires

In order to achieve the aim of establishing the current position in England on HTHH, questionnaire surveys were designed to elicit the required information from HAs, Trusts and the commercial home care companies.

3.2.3.3.2 Development of the Health Authority Questionnaire

The Pharmaceutical and Medical Advisers and Contracts Managers of HAs were the people known to be involved in the implementation of EL(95)5 [41]. It was therefore decided to aim the questionnaire towards these HA employees. This formed Section 2 of the questionnaire survey of HAs described in Section 3.2.4.1.1. The questionnaires were distributed between April and September 1997.

3.2.3.3.3 Development Of The Trust Questionnaire

It was decided to aim the Trust questionnaire at hospital pharmacists as they were likely to be responsible for preparing home infusions in their aseptic production units and, more then any medical or nursing speciality, would know about the full scope of HTHH within their Trust.

The objectives of the questionnaire are listed in Section 3.2.2.2.

A questionnaire was drafted based upon EL(95)5 [41], the available literature, local knowledge and experience of contracting, discussions with Pharmaceutical and Medical Advisers of HAs throughout England and questions which had arisen as a result of the HA questionnaire.

Comments were solicited from pharmacists within the Plymouth Hospitals NHS Trust, pharmacists from neighbouring Trusts, the local Research Development

Support Unit, the Pharmaceutical Adviser of South and West Devon Health Authority and the supervisors of this project.

The pilot was prepared (Appendix 13) based upon their comments and sent to 10 pharmacists known to have had some involvement with HTHH. A covering letter was sent with each explaining the aims of the project and asking for their help in commenting on the design of the questionnaire. Comments were also solicited from a researcher in Keele who had just completed a questionnaire survey to purchasers on the contracting mechanisms for HTHH [42].

Of the 11 pilot questionnaires distributed 7 were returned. Most found the questionnaire "moderately easy" to complete. The first two questions were removed as it was commented that they were unclear and did not elicit the required information. They were subsequently covered by a telephone survey, (see below). The table in Question 3 seemed daunting to some and one suggested putting a tick box question first. This was tried but as all other questions referred to the patients in the first question it was not possible to do this. The table was pivoted to try to make it clearer. Ambiguous replies were received to some questions and so these questions were subdivided and better explained. A final version of the questionnaire was designed based upon the comments from the pilot (Appendix 14). The covering letter was also adapted to explain the content of EL(95)5 [41], as it was commented that the pharmacists completing the questionnaire may not have received the Executive Letter from their Chief Pharmacist.

It was difficult to know how to target the questionnaire to those Trusts that had an input into HTHH. If the questionnaire was sent to all Trusts, those with no involvement would be unlikely to respond. This would make it difficult to extrapolate results with any degree of accuracy. In order to find out how many acute and community Trusts were involved with HTHH an initial telephone survey was conducted. This was followed up with a written questionnaire to those Trusts who were involved with HTHH. Ambulance Trusts, Learning Disabilities Trusts and Mental Health Trusts were excluded from the survey.

A number of sources for identifying the Trusts and the person to contact within the Trust were considered. These included asking the Regional Pharmaceutical Advisers for lists of the Trusts and Chief Pharmacists for their region, using Chemist and Druggist, Bourne's Directory, the Hospital and Health Services Year Book, the NHS Executive Regional Directories for 1997/98 or finding out if there was a list of hospitals with MCA Special's Licences. The NHS Executive Regional Directories were more complete and up-to-date than any other available source and using these was consistent with the method used for identifying HAs. A list was drawn up of 349 Trusts for the telephone survey. 79 Trusts were excluded from the survey on the basis that they were Ambulance Trusts, Learning Disability Trusts or Mental Health Trusts.

A structured interview questionnaire was designed for the telephone survey (Appendix 15) but after a pilot, which involved telephoning 10 Trusts it became apparent that this structured, formal approach was not flexible enough to obtain the required information. A flow chart (Appendix 16) was drawn based upon this trial and used for subsequent telephone calls. It gave a structured approach to obtaining the correct person to answer questions regarding HTHH. If the Trust did not have a Pharmacy Department an attempt was made to establish who provided pharmacy services to the Trust. It was decided that the pharmacist responsible for aseptic services would be most likely to know whether infusions were being used by any group of patients at home. If there was not an aseptic service the researcher asked to speak to one of the pharmacists and asked them who the most appropriate person to speak to would be.

Pharmacists (or in a small number of cases pharmacy technicians) of Trusts who were involved with the care of HTHH patients were asked if they would complete the written questionnaire (Appendix 14). This was posted to them as soon as possible after the telephone call.

The Trusts were telephoned over the period November-December 1997 and a questionnaire posted out to the named contact on the same or the following day. By 13 February 1998, 77 had been received, a reminder letter was sent to the remaining 90 Trusts.

A difficulty arose when a Trust had distinct units which functioned independently from each other such as Guy's and St Thomas's Trust. One questionnaire was sent to each hospital. The data was collected over the time period November 1997 to April 1998.

3.2.3.3.4 Development of the Commercial Home Care Company Survey

There were six commercial companies providing HTHH in England at the time of this survey. Competition for contracts meant that the companies may not have been willing to divulge certain information which may be commercially sensitive. This questionnaire was designed in consultation with two companies so that the questionnaire was developed within these limitations. The same two companies commented on a pilot questionnaire that was then used to develop the final questionnaire (Appendix 17). This was sent by post or delivered in person to all six commercial providers. Non-responders were followed up by telephone after 6 weeks.

3.2.3.4 Interpreting the Results/Coding the data

A similar approach was taken to that used to code the shared care data described in Section 2.2.4.4.2.

3.2.3.4.1 Health Authority Questionnaire

Coding of the qualitative comments received was performed by a group consisting of

a) 2 Trust pharmacists from different NHS Trusts
b) 1 HA Pharmaceutical Adviser
c) (1 Commercial Home Care Company nurse who was unfortunately called away shortly after the meeting had started).

The meeting was recorded on audiotape to allow further analysis of how decisions were reached.

3.2.3.4.2 Trust Questionnaire

Qualitative data was coded by the same group of people who coded the HA data at the same meeting (section 3.2.3.4.1).

Question 1 of the Trust Questionnaire (Appendix 14) asked respondents to identify who provided various aspects of care for HTHH patients. Many Trusts gave very similar answers or answers with the same meaning such as "hospital doctor" and "cancer unit doctor". The researcher coded these answers. This method of coding was validated by asking a home care pharmacist and a pharmacy technician involved with home infusions to independently code the answers to the first three parts of the question. The coding was compared and as there were very few discrepancies, the researcher went on to code the remaining data in the same manner. Where there were answers that were difficult to code or ambiguous a group decision was made by the researcher, home care pharmacist and pharmacy technician.

The results of the Trust questionnaire were validated by comparing the answers given during the telephone survey with those obtained on the postal questionnaire from the same Trust 20% of the answers were compared (Appendix 21). A computer was used to generate 18 random survey numbers from those returned and the information obtained in the telephone survey was compared with that later obtained from the same Trust in answer to the written survey.

3.2.3.4.3 Commercial Company Questionnaire

As there were so few commercial providers of HTHH the qualitative comments were not coded.

3.2.4 Results

3.2.4.1 Health Authority Survey

3.2.4.1.1 Response Rate

The questionnaires were returned over the time period April 1997 to February 1998. The response rate to this survey is discussed in Section 2.2.5.1.1. Many of the HAs did not answer questions regarding numbers of patients under the jurisdiction of their HA receiving the various home infusions.

27/87 (31.0%) HAs either could not or did not answer Section 2 Question 1 of the Health Authority questionnaire (Appendix 2) regarding numbers of patients receiving HTHH. In 9 cases it was left blank, 10 made comments regarding the Trusts. Many had handed the responsibility over to the Trusts and therefore did not know how many patients were being treated at home and the cost of their therapy, 5 made comments such as "no idea", "exact figures not available" and 4 said that the person who knew was not available or would have to be asked. Table 3.2 shows in more detail the responses for each drug/condition.

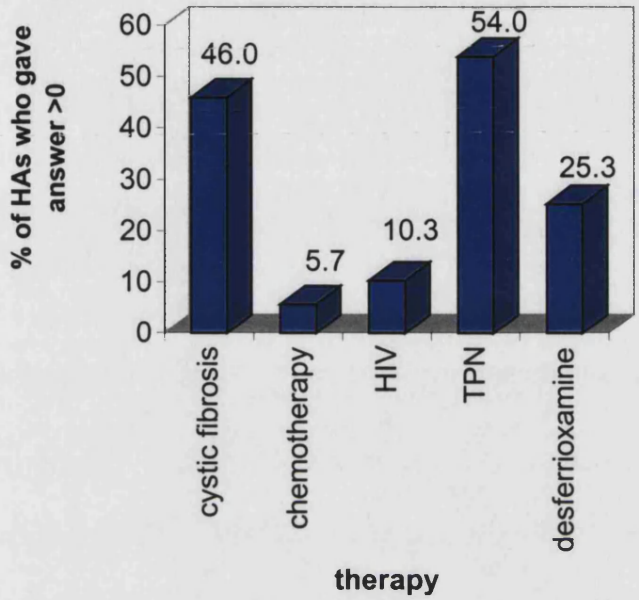
Table 3.2: HA Questionnaire: Number Of Responses To Question Asking Numbers Of Patients Receiving HTHH And Cost Of Their Treatment

(n=87)	didn't know or no answer		answer	
cystic fibrosis	43	49%	44	51%
chemotherapy	67	77%	20	23%
HIV	66	76%	21	24%
TPN	35	40%	52	60%
desferrioxamine	54	62%	33	38%

3.2.4.1.2 Numbers of Patients

Figure 3.2 shows the percentage of HAs treating patients with the various HTHH therapies. 54% had one or more patients on home TPN or specialised enteral feeds and 46% had patients being treated at home with antibiotics for cystic fibrosis.

Figure 3.2: HA Questionnaire, Proportion Of HAs treating Patients With Various HTHH Therapies



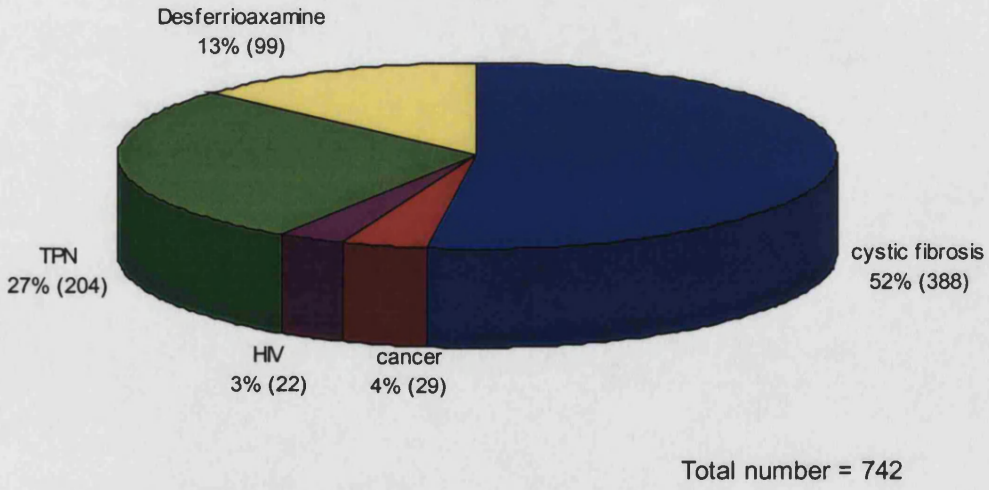
The numbers of patients being treated at home with various therapies is shown in Figure 3.3. Some HAs gave a range as an answer in which case the mid-point of that range has been included, others gave the answer "varies" and those answers have been excluded. Table 3.3 shows numbers of patients being treated with HTHH according to the HA survey.

Table 3.3 Current Number Of Patients Being Treated At Home, HA Questionnaire

n=87	total	mean*	upper limit of range
cystic fibrosis	388	9.0	50
chemotherapy	29	1.9	18
HIV	22	1.4	6
TPN	204	4.2	21
desferrioxamine	99	3.3	25

*total no of patients currently being treated divided by no of HAs who gave an answer >0

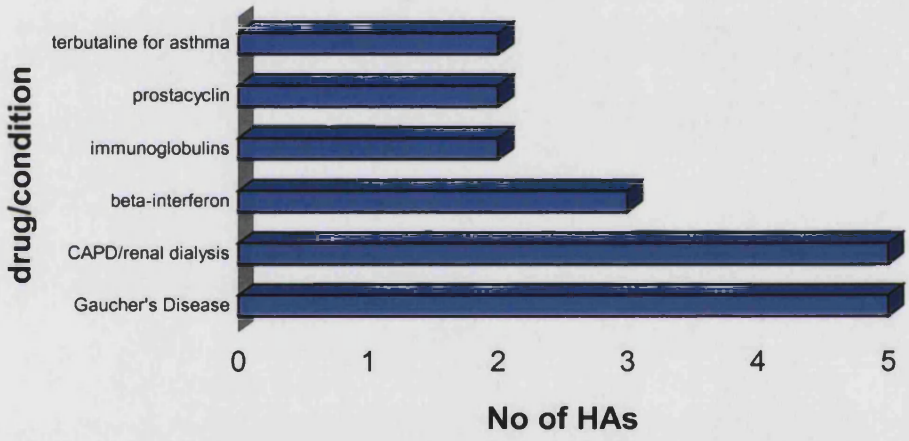
Figure 3.3: HA Questionnaire, Number Of Patients Receiving HTHH



3.2.4.1.3 Other Indications For Home Infusions

Other conditions and drugs provided in the domicillary setting are shown in Figure 3.4. There were few patients being treated with HTHH for other conditions. The two most commonly specified therapies were enzymes for Gaucher's disease and continuous ambulatory peritoneal dialysis (CAPD). (CAPD was covered under EL(95)5 [41] but this study has concentrated on infusions of drugs in the home setting and it is therefore outside the scope of this research). Those not shown in the graph because they were only mentioned by one HA were enteral feeding, intrathecal baclofen, calcium gluconate infusions for ricketts, home oxygen and paediatric Still's disease.

Figure 3.4: Health Authority Questionnaire, Other Home Infusions



3.2.4.1.4 Expenditure On Home Infusions

The expenditure by HAs on the various home therapies can be seen in Figure 3.5. Home TPN was the area of highest expenditure. The largest peak was for HAs who spent under £50K a year on home antibiotic infusions for cystic fibrosis patients. The expenditure by HAs on other home therapies is shown in Table 3.4.

Figure 3.5: Health Authority Survey, Expenditure on HTHH

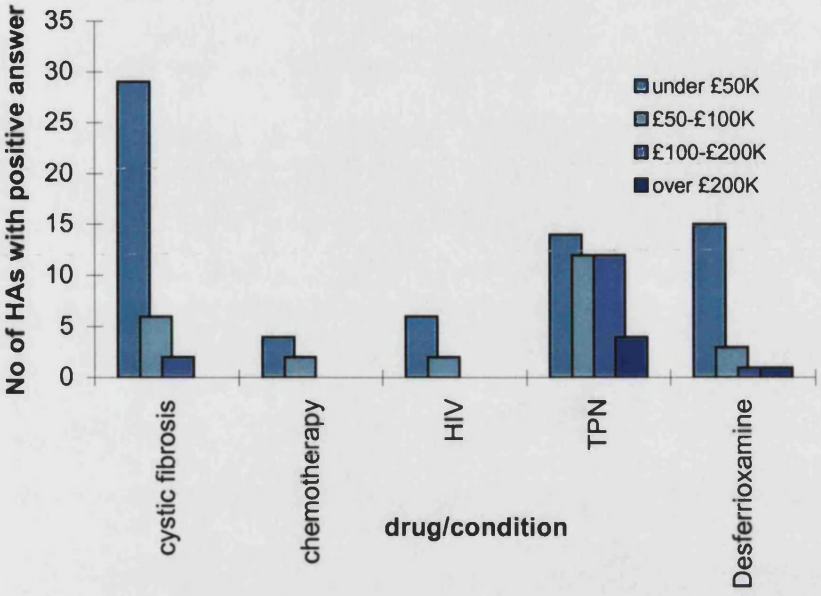


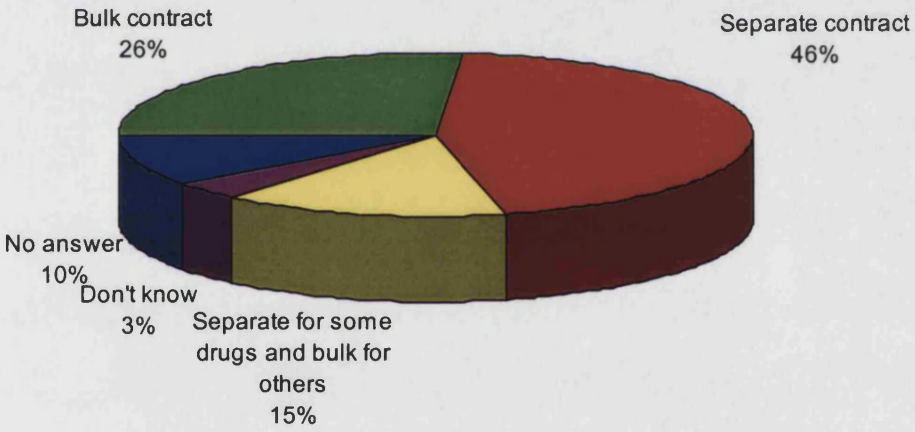
Table 3.4, Expenditure By Health Authorities On Other Home Therapies

	No of patients	<£50K	£50-£100K	£100-£200K	>£200K
Gaucher's disease	2				✓
	2			✓	
	2	cost not specified			
	3			✓	
	2				✓
CAPD/renal dialysis	not specified				✓
	40		✓		
	20			✓	
	42	✓			
Beta Interferon	7		✓		
	42				✓
	3	cost not specified			
Immunoglobulins	1	✓			
	2	✓			
Prostacyclin	1		✓		
	1				✓
Terbutaline for asthma	7		✓		
	not specified	✓			

3.2.4.1.5 Contracting

It was difficult to interpret the answers to the question regarding whether HTHH was purchased as a separate contract or as part of a bulk contract by the HA. They are listed in Appendix 18. Figure 3.6 shows a broad interpretation of the answers given, coded by the researcher. This does show that the majority of HAs contract for these services as a separate contract but over a quarter of respondents have just added the money from top-slicing GP budgets in 1995 to their bulk contracts with the Trusts and passed on the responsibility for contracting for/providing packages of care for these patients.

Figure 3.6 Health Authority Questionnaire, HA Contracts for the Provision of HTHH



None of the 87 HAs knew of any GPs who directly purchase HTHH for their patients.

3.2.4.1.6 Future Plans For HTHH

When asked if the HA had any future plans for the care of these patients only 17 (20%) said yes. The comments given are shown in Table 3.5.

Table 3.5: Future Plans Of HAs For The Care Of Patients Receiving HTHH

survey number	future plans	comments
17	Yes	We are allowing diversity of provision dependent on circumstances. May consider moving responsibility to Trusts but that has inherent difficulties.
24	Yes	May consider a competitive tendering exercise.
100	Yes	Service going out to tender, contract to commence 1/4/98.
5	No	New patients identified by Trusts as requiring hi-tech home health care would be the responsibility of individual clinicians to agree the most appropriate mechanism for providing this care in consultation with hospital pharmacists etc
41	No	*NB. Local Trust were sent copy of questionnaire and answered yes*
73	No	Initially wanted to move away from companies, now decided it's easier to keep patients with the provider that they are used to. Currently just watching.
88	No	All so varied an overall approach seems difficult.
103	No	Not at the moment.
113	No	Patients have long term illness
61/86		don't know

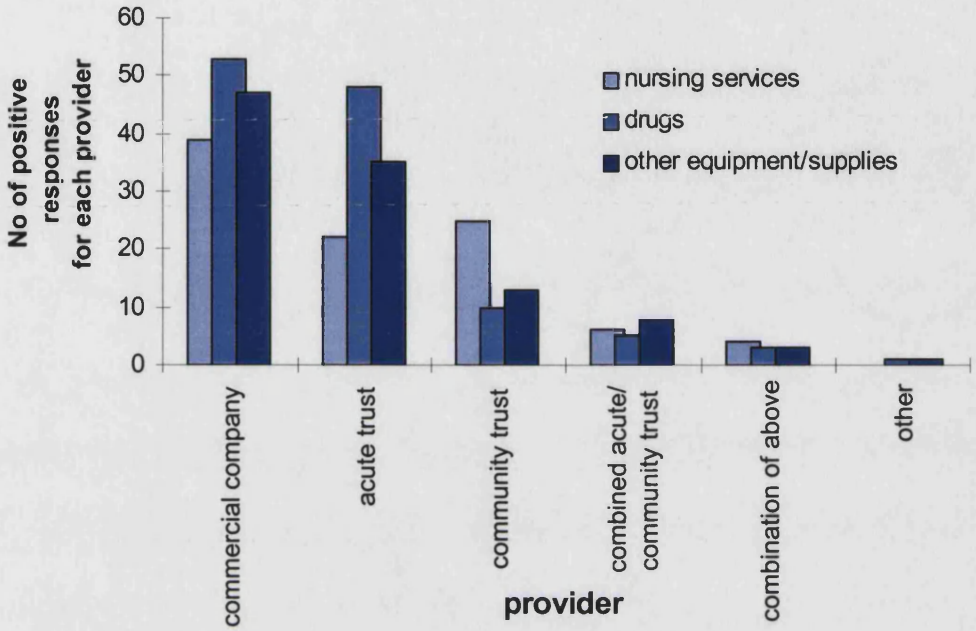
3.2.4.1.7 Providers of HTHH

It appears from this data that it is the commercial providers who provide most of the "packages of care" to patients at home (Table 3.6, Figure 3.7). Commercial companies were the top providers of nursing services, drugs and other equipment and supplies. They were followed closely by the acute Trusts, especially in the area of drug supply.

Table 3.6: Providers Of HTHH, HA Questionnaire

	nursing services	drugs	other equipment/ supplies
commercial company	39	53	47
acute trust	22	48	35
community trust	25	10	13
combined acute/community trust	6	5	8
combination of above	4	3	3
other	0	1	1

Figure 3.7: HA Questionnaire, Provision of Services to Patients at Home



3.2.4.1.8 Successful and Difficult Aspects of HTHH

The qualitative comments received regarding the aspects of HTHH that had been difficult/problematic or successful and other comments on the subject of HTHH were coded as described in Section 3.2.3.4.1. They are listed in Appendix 3, in the format in which they were given to the group for coding. The coding and the coding frame developed by the group are shown in Appendix 20.

3.2.4.2 Trust Questionnaire

3.2.4.2.1 Validation Of The Data

Comparison of the answers obtained to the written survey and the telephone survey from 18 randomly selected Trusts are shown in Appendix 21. It can be seen that on 10 out of 18 (55.6%) of occasions the questionnaire was completed by the same person who answered the telephone survey, on 6 occasions it was impossible to tell who filled in the questionnaire as no name was given and on 2 occasions the questionnaire was filled in by a different person. On both of these occasions the questionnaire was handed on to the Chief Pharmacist of the Trust to complete.

There are discrepancies in the data but they are broadly in line. Some discrepancies would be expected as the written questionnaire asks for current numbers of patients whereas the telephone survey asked if patients under the care of the Trust were ever treated with HTHH.

3.2.4.2.2 Trusts Providing HTHH

At the time of the survey there were 428 NHS Trusts in England. 79 of these were excluded from the survey being ambulance, learning disabilities or mental health Trusts. When telephoned 167 of the 349 Trusts said that they were providing or had provided some sort of HTHH service (see results of telephone survey Appendix 22). These Trusts were sent the written questionnaire (Appendix 14) as described in Section 3.2.3.3.3.

3.2.4.2.3 Response Rate

105 questionnaires were received from 104 Trusts. 167 written questionnaires were sent out giving a response rate of 63%. There were 94 evaluable questionnaires giving a revised response rate of 56% (Table 4.6).

Table 3.7: Responses From Trusts By Region

Region	Number of evaluable surveys returned	No. of questionnaires sent out	% returned
Anglia & Oxford	11	18	61
Northern & Yorkshire	8	23	35
North Thames	16*	26	62
North West	15	27	56
South & West	14	19	74
South Thames	9	19	47
Trent	11	18	61
West Midlands	10	17	59
Total	94	167	56

*16 questionnaires were returned from 17 Trusts. For subsequent analysis these will be included as if they were separate Trusts.

Even after the telephone survey to screen out Trusts with no patients being treated at home 11 questionnaires were returned that were not evaluable. These are shown in Table 3.8.

Table 3.8: Surveys Not Evaluated

Survey No	
2	Blank with letter explaining that patients dealt with by local acute trust.
33	No HTHH, Community Trust, rehabilitation and psychiatry only
46	HTHH program not up and running yet.
88	TPN ST Marks, Oncology Hammersmith, Collaborative care team administer antibiotics at home, HIV St Mary's, Sickle cell Centre in Brent.
133	Will be dealt with in the Thameside questionnaire.
145	Patients receiving HTHH go to Christies.
229	Community Trust, all HTHH initiated by acute Trust, the only involvement the community trust has is of the district nurses.
262	No involvement, no patients.
297	No HTHH patients.
312	Community Trust can't get hold of the answers.
365	No patients in the past year, gave home TPN years ago, very occasionally have home chemotherapy arranged by oncology nurse and pharmacy.

3.2.4.2.4 Number of Patients Receiving Home Infusions

The numbers of patients receiving infusions at home or as outpatients are shown in Table 3.9.

Table 3.9: Numbers Of Patients Receiving HTHH, Trust Questionnaire

Drug/condition	Actual number	Number normalised*	Upper end of range
antibiotics for cystic fibrosis	530	879	130
chemotherapy	597	990	150
antivirals for HIV	50	83	12
adults receiving TPN	230	381	84
children receiving TPN	41	68	12
Desferrioxamine	159	264	58

*167 sent questionnaires - 11 no involvement = 156 Trusts involved with HTHH

94/156 = 60.3% normalised to 100%. NB. Does not take into account that some non-responders may not provide HTHH.

3.2.4.2.4.1 Other Home Infusions

Other therapies that patients were receiving at home not mentioned in the questionnaire are shown in Table 3.10.

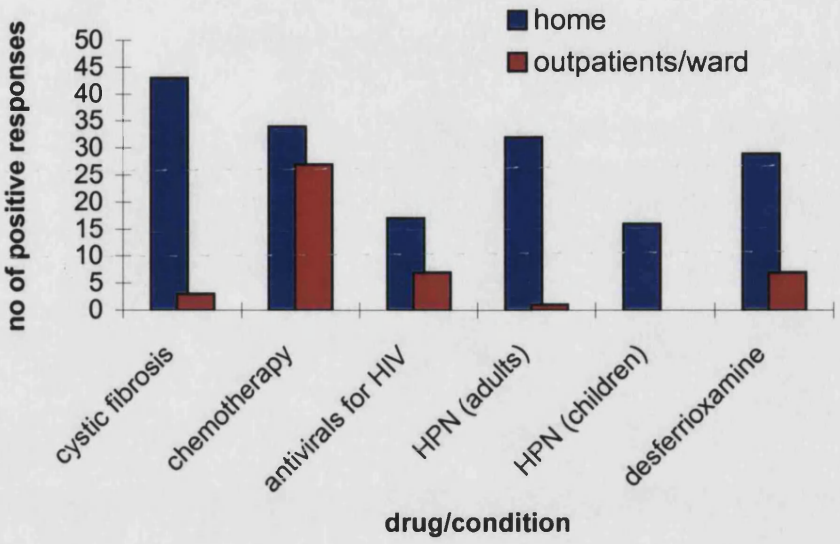
Table 3.10: Other Home Infusions, Trust Questionnaire

Drug/condition	No of Trusts	No of patients	Where therapy administered
Immunoglobulin	5	8-9	all at home
Enzymes for Gaucher's Disease	5	6	all at home
Pain relief in palliative care	6	>27	all at home
Terbutaline	2	>14	all at home
Aminophylline	1	1	all at home
Apomorphine	1	not specified	all at home
CMV treatment for transplant patients	2	6	all at home
G-CSF	1	12	all at home
Magnesium infusions	1	1	all at home
Sodium chloride 0.9% infusions	1	1	all at home
Iloprost	1	1	all at home
CAPD	1	38	all at home
home inotropes	1	2	in local hospitals
methotrexate - arthritis	2	>15	at GP surgeries
subcutaneous cytotoxic therapy	1	not specified	all at home
nebulised colomycin	1	not specified	all at home
line locs for oncology patients	1	2-3	all at home

3.2.4.2.5 Where do patients receive their drug therapy?

Most patients were receiving their therapy at home, but it was commented that often patients would start therapy as an inpatient and then be discharged and either receive therapy as an outpatient or at home. For chemotherapy it was difficult to interpret the data as ambulatory pumps were often set up in the hospital and the patient then received most of the therapy outside of the hospital. The perception of where the drug was administered in this situation varied. The data was coded as described in Section 3.2.3.4.2. The results of this are shown in Figure 3.8.

Figure 3.8: Trust Questionnaire, Where Do Patients Receive Their Drug Therapy?

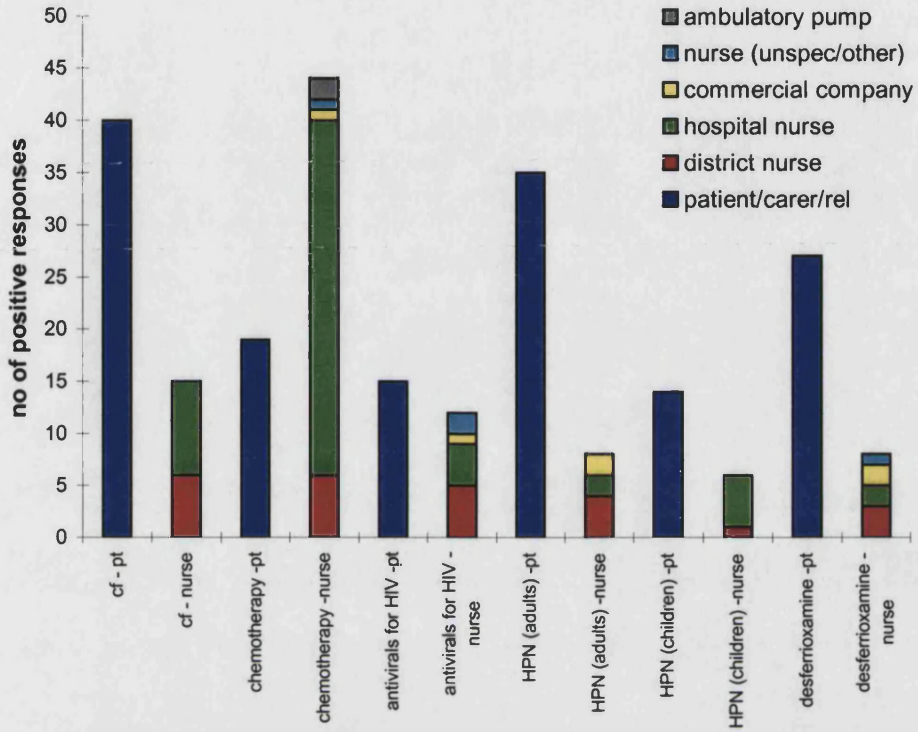


3.2.4.2.6 Who Provides Various Aspects Of Their Care?

3.2.4.2.6.1 Who Administers the Therapy?

In all but one instance it was the patient or a relative or carer who most often administered the therapy. The exception was chemotherapy which was more often administered by a nurse. Again it was difficult to interpret the answers given to this question because often the patient came to the hospital to have a pump reservoir changed or set up and there were differences as to who was perceived to be administering therapy. It can be seen from Figure 3.9 that when therapy was administered by a nurse it was most commonly by a hospital or district nurse.

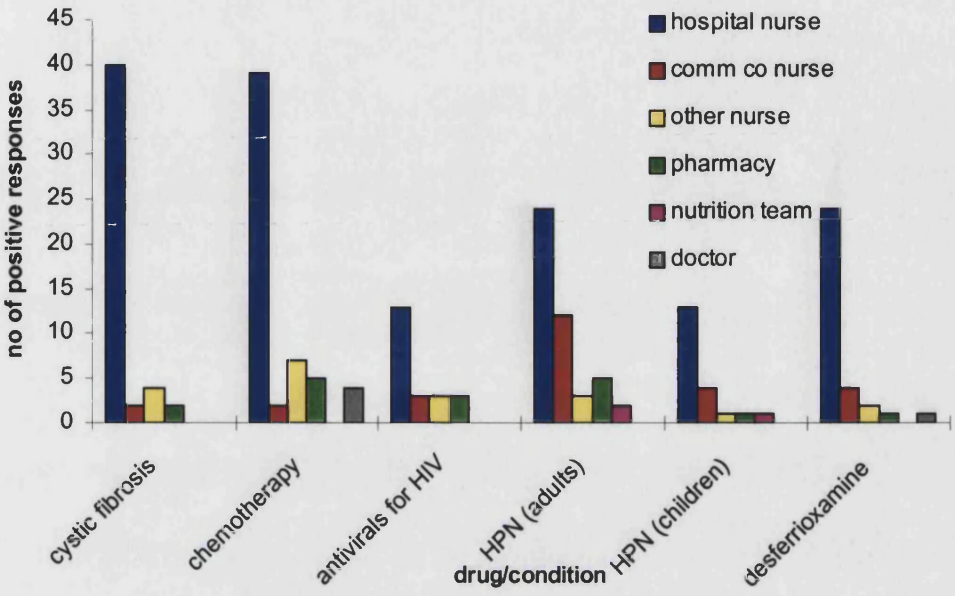
Figure 3.9: Trust Questionnaire, Who Administers Therapy?



3.2.4.2.6.2 Who is responsible for training the patient

Training of the patients in all instances was undertaken far more frequently by a hospital nurse than by any other person. Commercial company nurses, other nurses and pharmacists featured much more frequently than doctors (Figure 3.10).

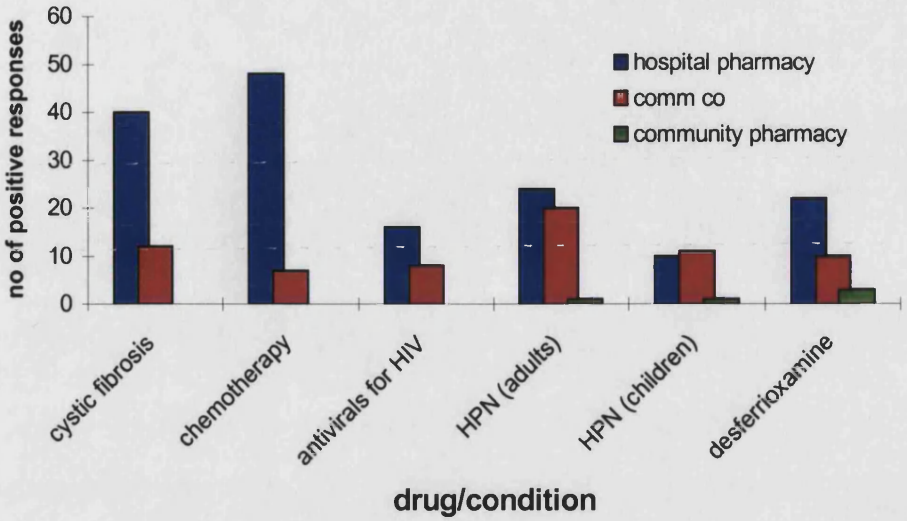
Figure 3.10: Trust Questionnaire, Who Is Responsible For Training The Patient?



3.2.4.2.6.3 Who provides the drugs?

The drugs were most often supplied by a hospital pharmacy department but large numbers were also supplied by commercial home care companies (Figure 3.11). In the case of adult HPN almost as many Trusts said that a commercial company supplied the TPN as said that it was supplied by the Trust. TPN for children was supplied more often by commercial companies than hospital pharmacy departments. Community pharmacists were said to be supplying children's TPN and desferrioxamine.

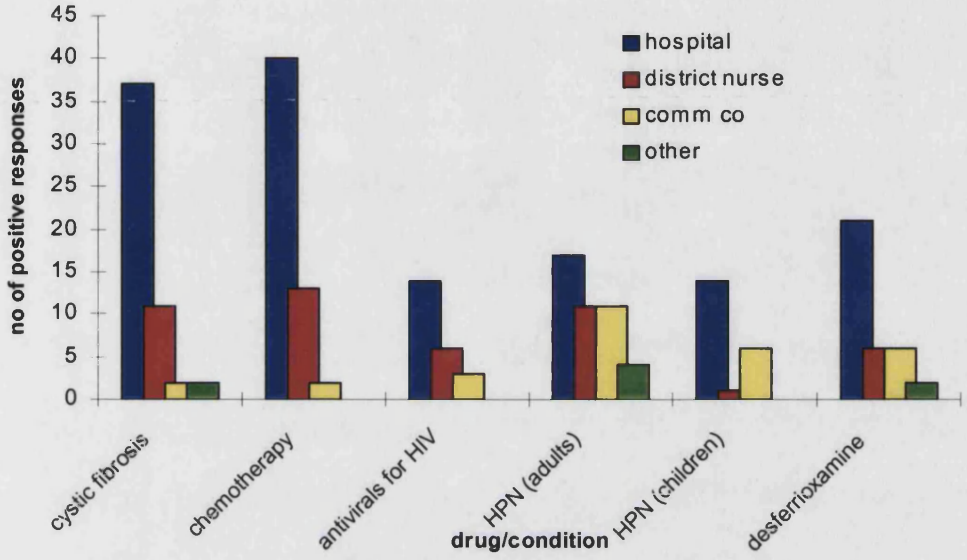
Figure 3.11: Trust Questionnaire, Who Provides the Drugs?



3.2.4.2.6.4 Who provides the nursing care?

Nursing care was most commonly provided, for all the specified indications, by hospital nurses (Figure 3.12). These varied from nurses on the wards or in outpatients to various kinds of specialist nurses and community liaison nurses. Although respondents were asked to specify, in certain cases it was difficult to tell whether the nurses were hospital or primary care based e.g. "children's community nurse". The other category in Figure 3.12 includes family or parents providing nursing care and patients who did not require nursing care e.g. a GP receiving home therapy.

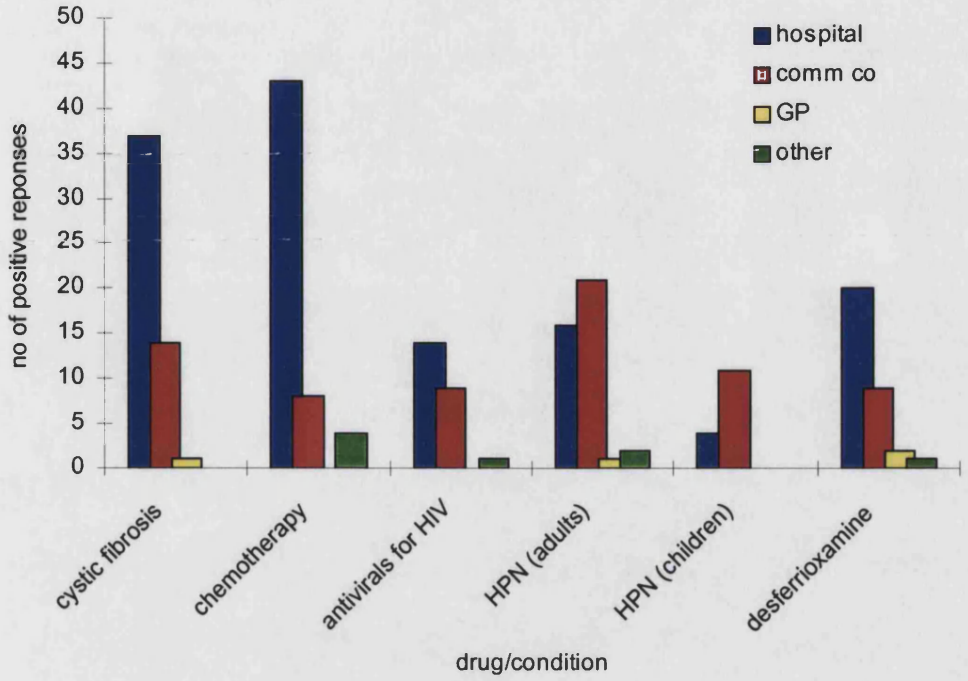
Figure 3.12: Trust Questionnaire, Who Provides the Nursing Care?



3.2.4.2.6.5 Who provides the equipment and supplies?

When asked who provides equipment and supplies the answers were different for the different groups of patients (Figure 3.13). It was more common for HPN patients (both children and adults) to receive supplies from a commercial home care company whereas the other patients more commonly received supplies via the hospital. This happened in various ways via the pharmacy, stores departments, nursing staff, wards or outpatients. Some patients were obtaining equipment and supplies from their GP.

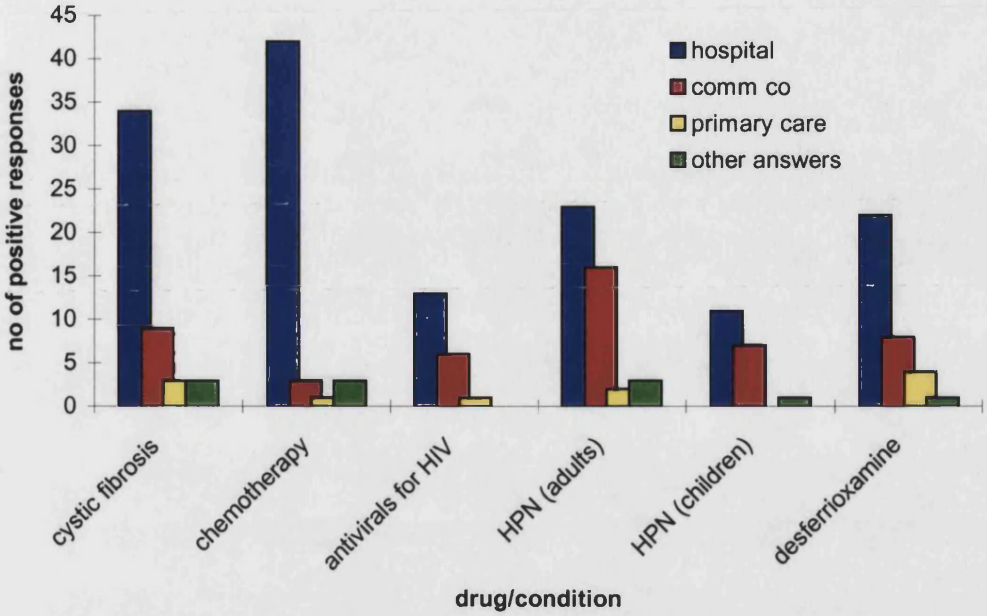
Figure 3.13: Trust Questionnaire, Who Provides Equipment and Supplies?



3.2.4.2.6.6 Who provides a 24 hour help-line?

A 24 hour help line was again most commonly provided by the hospital for all groups of patients but in all cases commercial companies were the second largest provider (Figure 3.14). The "other" section of the graph includes 6 Trusts who did not know who provided a 24 hour help line for these patients and also "Intensive Home Nursing Service" and "community liaison team" which were difficult to fit into the primary or secondary care categories.

Figure 3.14: Trust Questionnaire, Who provides A 24 Hour Help Line?



3.2.4.2.7 Expenditure

The questionnaire asked for the approximate annual expenditure for a total package of care for all patients in the group to the nearest £10,000. It also said "if you only supply part of this service please specify which part and give the cost".

The figures given for expenditure on home infusions are shown in Appendix 23. Many did not give any information on the cost of home infusions (Table 3.11).

Table 3.11 Proportion of Trusts Providing Information on their Expenditure

	Number of Trusts with >0 patients receiving home infusions	Figure given for expenditure n=94	% giving figure for their expenditure	No answer/ didn't know/ unable to supply information n=94
Cystic fibrosis	43	22	51.2%	72 (76.5%)
Chemotherapy	39	15	38.5%	79 (84.0%)
HIV	14	8	57.1%	86 (91.4%)
TPN adults	34	15	44.1%	79 (84.0%)
TPN children	14	9	64.3%	85 (90.0%)
Desferrioxamine	30	15	50.0%	79 (84.0%)

3.2.4.2.8 Role of the Pharmacist

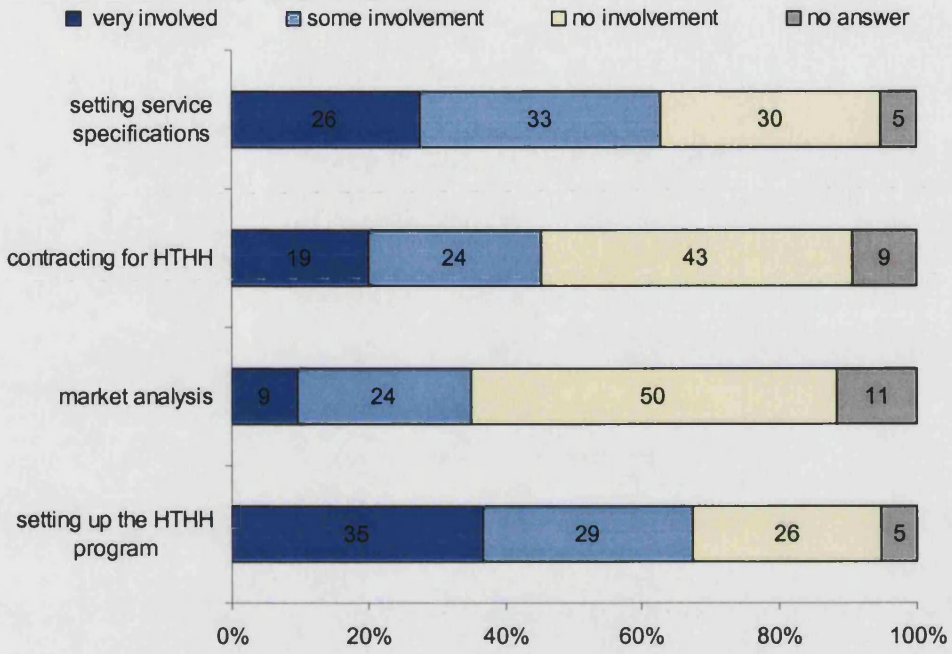
Figure 3.15 and Table 3.12 show the response to Question 2 of the survey of NHS Trusts. This question asked, "Which aspects of HTHH have pharmacists in your Trust been involved with?" The clinical, co-ordination and communication and supply areas were where pharmacists had the greatest involvement.

If pharmacists had no involvement respondents were asked to specify who is responsible. Often this section was not completed. Most said that specialist nurses or consultants were responsible for setting up the service and market analysis, directorate and business managers were involved with contracting and setting service specifications.

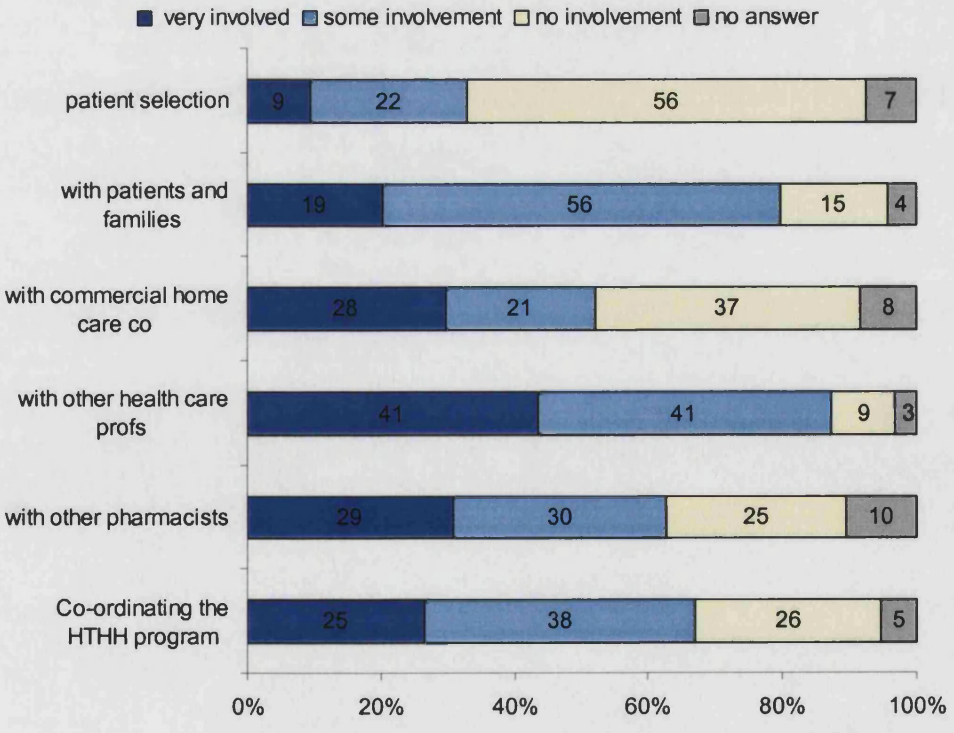
Nurses and occasionally doctors were responsible for co-ordinating the HTHH programme and communication with patients, their families and other health care staff. Specialist nurses and commercial providers were responsible for education and if the pharmacy did not supply drugs it was almost always a commercial company that supplied them.

Figure 3.15, Role of the Pharmacist in Hi-the Health Care at Home

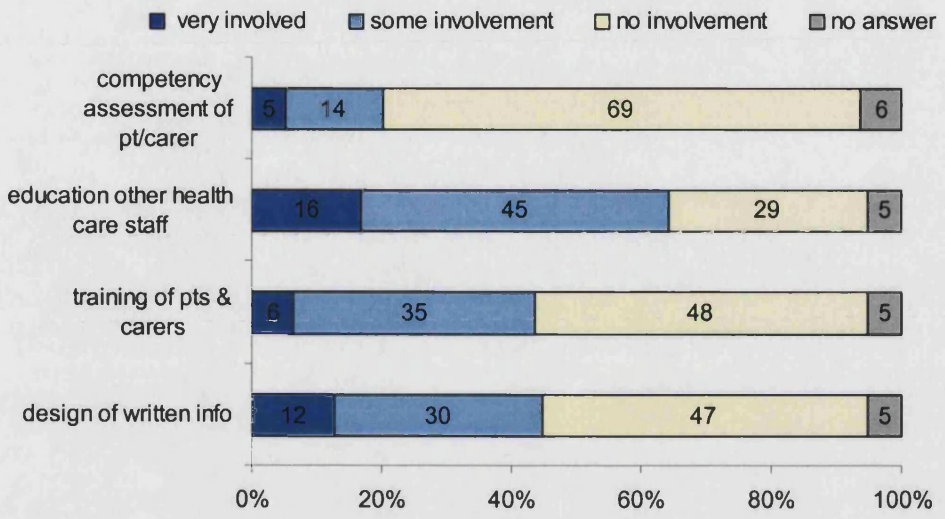
a) Contracting



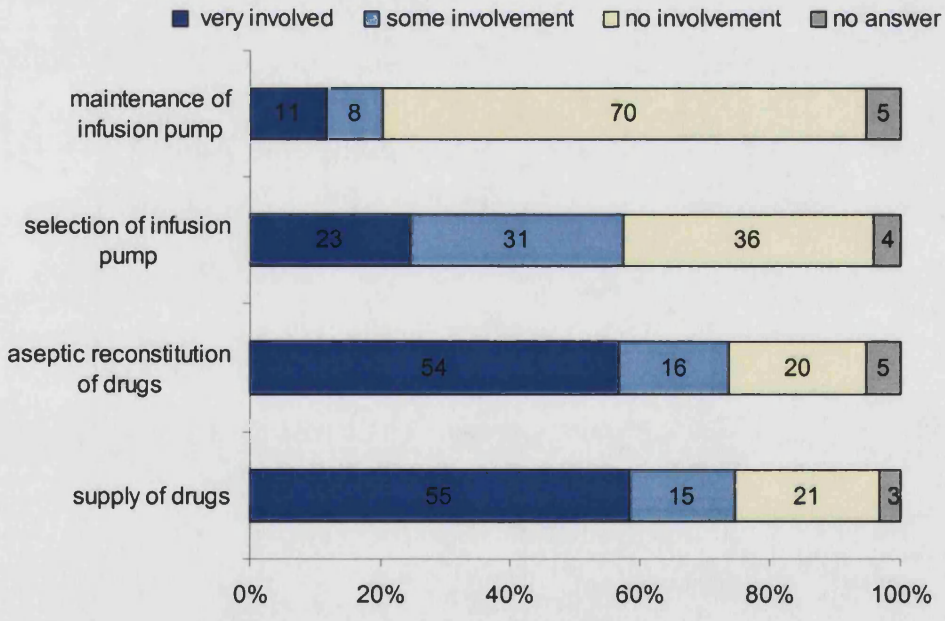
b) Co-ordination and Communication



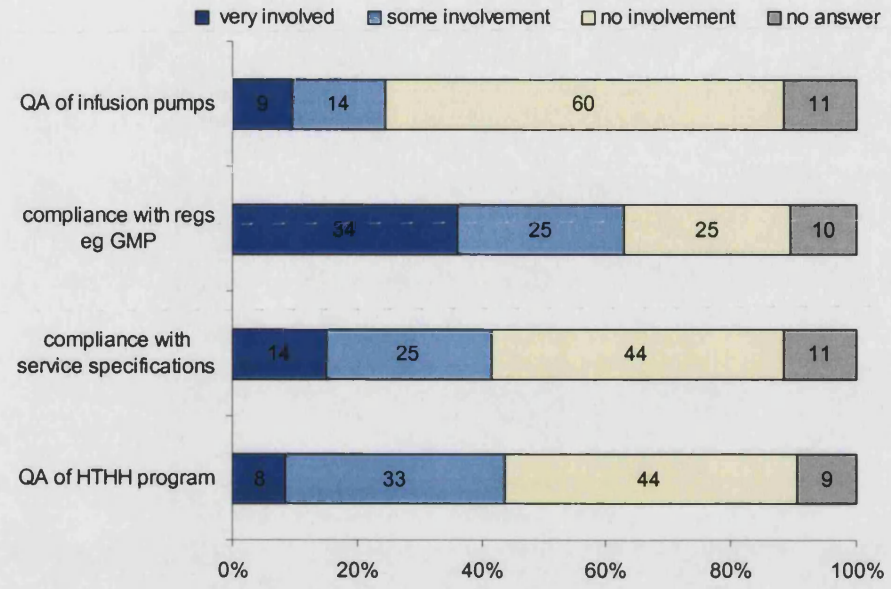
c) Education



d) Supply



e) Quality Assurance



f) Clinical

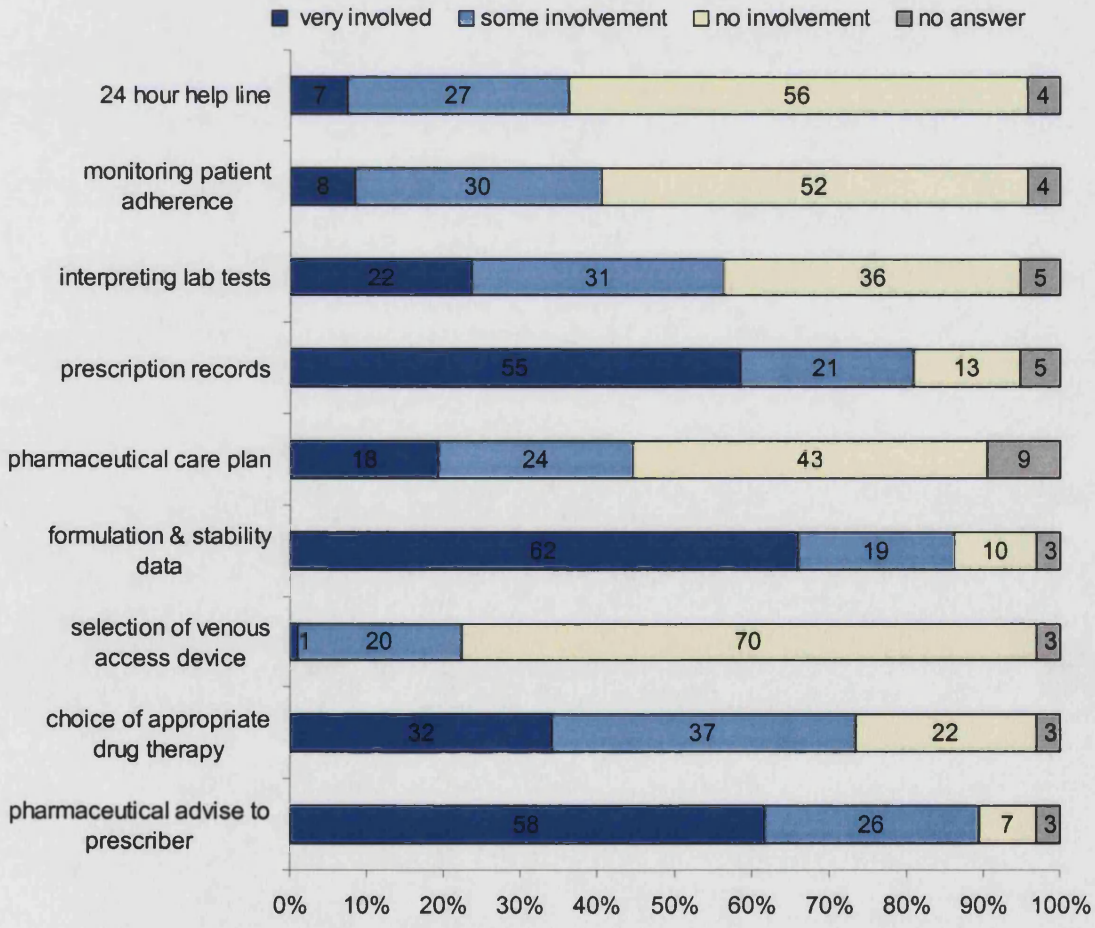


Table 3.12, Role of the Pharmacist in Hi-tech Health Care at Home

n=94	very involved	some involvement	no involvement	no answer	Some + very
CONTRACTING					
setting up the HTHH program*	35	29	26	5	64
market analysis	9	24	50	11	33
contracting for HTHH*	19	24	43	9	43
setting service specifications	26	33	30	5	59
CO-ORDINATION AND COMMUNICATION					
Co-ordinating the HTHH program	25	38	26	5	63
with other pharmacists	29	30	25	10	59
with other health care profs	41	41	9	3	82
with commercial home care co	28	21	37	8	49
with patients and families	19	56	15	4	75
patient selection	9	22	56	7	31
EDUCATION					
design of written info	12	30	47	5	42
training of pts & carers	6	35	48	5	41
education other health care staff*	16	45	29	5	61
competency assessment of pt/carer	5	14	69	6	19
SUPPLY					
supply of drugs	55	15	21	3	70
aseptic reconstitution of drugs*	54	16	20	5	70
selection of infusion pump	23	31	36	4	54
maintenance of infusion pump	11	8	70	5	19
QUALITY ASSURANCE					
QA of HTHH program	8	33	44	9	41
compliance with service specifications	14	25	44	11	39
compliance with regs e.g. GMP	34	25	25	10	59
QA of infusion pumps	9	14	60	11	23
CLINICAL					
pharmaceutical advise to prescriber	58	26	7	3	84
choice of appropriate drug therapy	32	37	22	3	69
selection of venous access device	1	20	70	3	21
formulation & stability data	62	19	10	3	81
pharmaceutical care plan	18	24	43	9	42
prescription records	55	21	13	5	76
interpreting lab tests	22	31	36	5	53
monitoring patient adherence	8	30	52	4	38
24 hour help line	7	27	56	4	34

* columns add up to 95 not 94 because some Trusts ticked more than one answer.

Two Trusts said that the commercial provider was responsible for quality assurance of the home care programme, other answers included ward staff, consultant, clinician, specialist nurse and business manager for the nutrition ward, four Trusts were unsure and two admitted that no-one was performing this task. Five Trusts named someone responsible for ensuring compliance with service specifications (home care company, business manager, ward staff, specialist nurse and consultant), one said they get general feedback, two said "not known", two "not done" and one said "no service specifications that I know of". Most said that medical electronics or commercial HTHH providers were responsible for quality assurance of the infusion pumps.

The clinical role was almost entirely performed by nursing and medical staff if not undertaken by the pharmacist. Home care companies, on-call doctors and ward staff provided a 24-hour help line for HTHH patients.

3.2.4.2.9 Patients outside the scope of EL(95)5 receiving home infusional therapy.

When asked " Do any patients outside the scope of EL(95)5 [41] receive home infusional therapy e.g. apomorphine for Parkinson's disease?", 10 of the 94 (10.6%) Trusts said yes, 6 gave no response to this question and 78 said no. The other drugs/conditions specified are listed in Table 3.13.

One Trust said that although oncology and haematology treatments should be included in EL(95)5 [41], the local HA does not include them and another stated that the list of treatments in EL(95)5 [41] was not exhaustive and therefore all home intravenous therapy comes under EL(95)5 [41].

Table 3.13: Patients Outside The Scope Of EL(95)5 Receiving Home Infusions, Trust Questionnaire

Drug/condition	No of Trusts who gave this answer
apomorphine	5
terminal care/pain relief (s/c & epidural)	5
immunoglobulins	2
Iloprost	2
erythropoietin	1
growth hormone	1
adrenaline/dopamine for transplant patients	1
Factor VIII	1
theophylline	1
baclofen	1
octreotide	1
enzymes for Gaucher's disease	1

3.2.4.2.10 Patients receiving HTHH prior to EL(95)5.

Are there any patients under the care of your Trust who were receiving HTHH prior to EL(95)5 [41] and continue to do so as part of a bulk contract e.g. chemotherapy?

15 gave no answer, 57 said no and 22 (23.4%) said yes. The drug/conditions specified are listed in Table 3.14.

Table 3.14: Patients Receiving HTHH Prior To EL(95)5, Trust Questionnaire

Drug/condition	No of Trusts who gave this answer
TPN	11
antibiotics for cystic fibrosis	8
chemotherapy infusions	6
CAPD	1
Thallassaemics	1
Baclofen	1
antivirals for HIV	1
All home patients	2

3.2.4.2.11 Reason Current Provider Chosen

Why was your current home care provider chosen to provide care for this group of patients?

The major reason was quality of service, as can be seen from Figure 3.16. Most Trusts gave more than one answer to this question. Other reasons for choosing the current home care provider are shown in Table 3.15.

Figure 3.16: Trust Questionnaire, Other Reason Current HTHH Provider Chosen

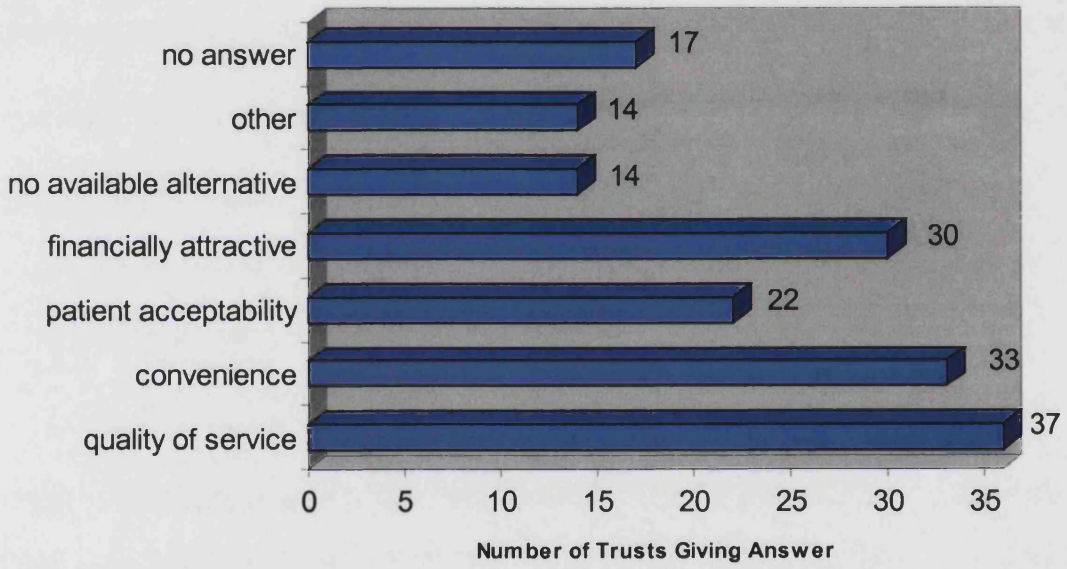


Table 3.15: Other Reasons for Providing A HTHH Service, Trust Questionnaire

Survey no	other reason for providing HTHH, specify
1	Experience in field; multinational
3	Contacts with HA
57	Unknown
66	No information
74	We do not currently use one for IVs (Caremark for enteral has been used).
90	Provided by pharmacy and hospital as not enough work to contract out.
100	No in house manufacturing capacity/no NHS alternative
111	Clinical indication continuous infusion of cytotoxic
118	Actually use 5 home care providers
124	We were unhappy with our previous provider and we were approached by this care provider to work in partnership with them with us providing the aseptic
158	Don't know
172	Dictated by which provider individual purchasers had drawn up a contract with.
177	Unknown - set up before in post
214	Small numbers and infrequent need mean that pharmacy is best able to meet needs of patient.
219	Above as partner with ourselves
222	It is an in house group set up for this purpose.
230	Contract decided by the HA ?parameters used?
232	Did not want to change.
241	Current system = pilot study of aseptic preparation by hospital pharmacy previously vials were supplied for reconstitution by parents at home.
258	Better treatment decided by consultants.
282	Developed from our aseptic service provision to inpatients. All patients were initially inpatients at the hospital.
283	No company currently used
317	We use a variety
344	TPN
349	At the time needed for our first TPN patient.
352	"Caremark" was recommended by one consultant at St Georges to the consultant here at .....
1005	Used hospital pharmacy staff

3.2.4.2.12 Shared Care Guidelines For HTHH

Do you have any guidelines for sharing the care of these patients between primary and secondary care?

10 (10.6%) of the 94 Trusts had any form of shared care guideline for patients being treated with HTHH. Table 3.16 shows further details from these 10 Trusts. 72 Trusts said they have no guidelines and 12 gave no answer to the question.

Table 3.16: Details of Shared Care Guidelines for HTHH, Trust Questionnaire

Survey no	shared care guidelines for HTHH?	Details and other comments
27	yes	We have developed guidelines for shared care of these patients. Document for GPs and document for hospital staff.
28	yes	Written guidelines on procedures, drugs, etc sent to GPs
74	yes	"Shared care" protocols being developed with local HA
98	yes	No of written protocols for some specific disorders.
172	yes	Shared care protocols - ganciclovir, foscarnet, amphotericin B
230	yes	Same shared care protocols as you!
337	yes	Details are determined individually according to the needs of each family.
349	yes	Shared care protocol based on one obtained from Grimsby Hospital, prior to EL(95)5 and then modified when EL(95)5 came into effect.
999	yes	If HIV patients want district nurse to set up infusions we train them in use of infusion devices.
2222	yes	Joint procedures/protocols
72	no	No primary care involvement
165	no	No formal guidelines
180	no	The nutrition guidelines.
223	no	Guidelines are being developed through area prescribing committee
323	no	Primary care will not agree to be involved.
327	no	Not yet
222		I'm not sure! I don't think so. We do it all!
227		Chose your commercial company carefully.
244		Some were drawn up before EL(95)5; now we do everything so they are obsolete! (for HIV only)

3.2.4.2.13 Audit to Measure Quality of Care

Is there an audit system in place to measure the quality of care received by these patients?

12 Trusts gave no answer, 4 didn't know, 18 said yes, 58 said no, 1 said "sort of" and 1 said "very few patients therefore patients questioned regularly and encouraged to report problems" (Figure 4.16).

When asked who specifies audit criteria the number of positive responses are shown below

HA	5
trust/provider unit	15
commercial company	4
other (patient/carer)	1

When asked who measures the quality of care received the number of positive responses are again shown below

HA	3
trust/provider unit	12
commercial company	4
other (patient/carer)	2

When asked "how is this measured?" 8 of the 18 HAs who gave an answer used a questionnaire. The answers given are listed in Table 3.17.

Table 3.17: Trust Questionnaire, How Is Quality Of Care Measured?

Survey no	How is quality of care measured?
1	Patient satisfaction
27	Patient questionnaire is our only audit tool at present.
74	Patient questionnaire - usually.
92	patient satisfaction questionnaire
98	May be some feedback from the HA
116	service assessed periodically
118	Questionnaires, patient groups etc
123	Questionnaires and monitoring of any problems.
124	Depends on what the individual Trust requires.
146	don't know!!
180	- see Business Manager
227	Very little known about it.
283	?Probably such small scale that feedback is easier and patients are actively followed up.
327	Regular questionnaires
337	Only just being set up - not complete.
349	Patient monitored clinically - U&E results from fortnightly blood samples and attends outpatient clinic to see the consultant to whom all hospital TPN patients are referred.
355	Questionnaire
2222	Patient questionnaire - F.U.

3.2.4.2.14 Audit to Measure Patient Outcomes

Is there an audit system in place to measure patient outcomes?

12 Trusts said yes, 57 said no and 25 gave no answer or did not know (Figure 4.16).

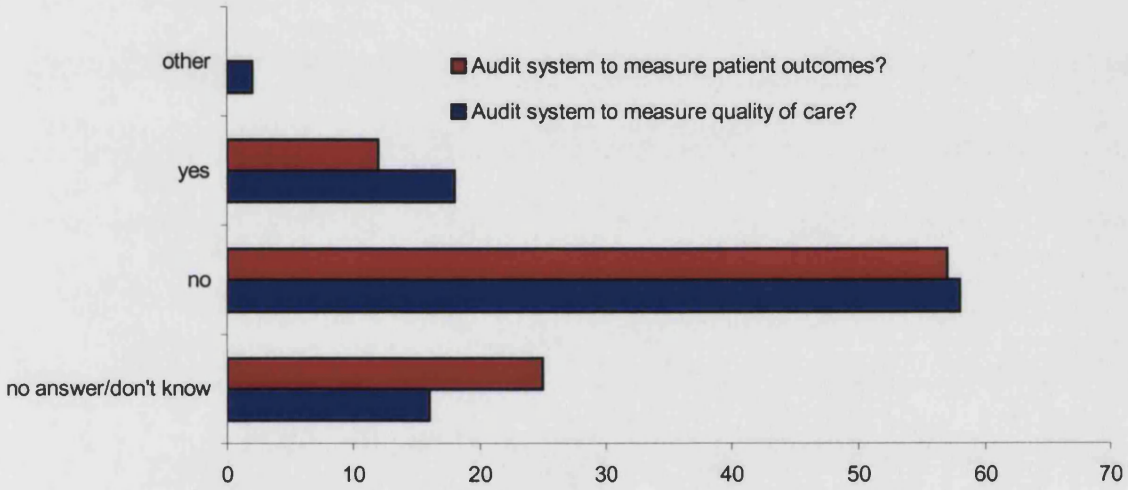
The responses to the question "who specifies the audit criteria" are shown below

HA	1
trust/provider unit	11
commercial company	0
other (patient's consultant/ national)	3

The positive responses to "who monitors patient outcomes?" were as follows

HA	2
trust/provider unit	12
commercial company	2
other (prescriber/nutritional support team/national)	3

Figure 3.17, Trust Questionnaire, Auditing of HTHH



3.2.4.2.14.1 How is this achieved?

76 trusts gave no answer. The answers of the 18 who did are listed in Table 3.18.

Table 3.18: Measurement of Patient Outcomes, How is this Achieved? Trust Questionnaire

Survey no	How patient outcomes are measured.
27	Long term follow-up of iv antibiotic patients.
72	Data collection on service - Clinical Outcomes
74	Not at the moment. It is hoped to address this with the shared care protocols under development.
83	Respiratory nurses assess informally.
98	Internal TPN audit
99	Unaware as pharmacy involvement nil.
180	Regular audit and review meetings
219	Informal review of patient records/history at routine clinic appointments
241	only really tried in paediatric cf patients - antibiotics given from syringes not as infusion therapy
258	Oncology patient survival rate/cancer cure.
282	Various small audits have been carried out by medics, nurses and pharmacists.
283	By default - pts reviewed regularly as outpatient therefore outcome visible
303	Formal annual audit of all TPN patients. Copies of report to all involved persons and recommendations.
321	Audit Department follow up chemotherapy patients, cystics are routinely monitored
327	via nursing audit system
337	Medical/nursing audit.
349	Patient monitored clinically - U&E results from fortnightly blood samples and attends outpatient clinic to see the consultant to whom all hospital TPN patients are referred.
2222	home data

3.2.4.2.15 Groups of Patients in Which Home Infusions Have Worked Best

In which group of patients has home infusion worked best and why?

The answers given to this question are given in Appendix 4. These results were coded as discussed in Section 3.2.3.4.2 and the coding frame developed is shown in Appendix 20. It can be seen from this coding frame that the main positive comment was that the service provided post EL(95)5 [41] was better than that provided before. Home TPN (22), chemotherapy infusions (14) and antibiotics for cystic fibrosis (11) were the therapies which had worked best. The data was also coded by the researcher as shown in Table 3.19. This also shows that TPN and chemotherapy were the home infusions considered to be most successful. The reasons for this were patient preference for being at home and the resulting increase in their quality of life and good organisation of the home infusion service.

Table 3.19: In Which Patients Have Home Infusions Worked best and Why?

What has worked best?	Number of comments
TPN	20
Chemotherapy	17
Antibiotics	9
HIV	6
Desferrioxamine	6
Terbutaline	1
Enzymes for Gaucher's disease	1
CAPD	1
Transplant recipients	1
Electrolyte replacement	1
Home epidurals	1
Paediatrics	1
All home patients	3
Limited Experience	4

Why?	Number of comments
Patients prefer to be at home/ can get on with life.	17
Frees up hospital beds/clinic time.	9
Good organisation and backup for home care programme	14
Motivated patients	8

3.2.4.2.16 Barriers to Providing HTHH

What are/have been the barriers in providing infusion therapy at home in your area?

The answers to this question are shown in Appendix 24. Again they were coded as described in Section 3.2.3.4.2. The major barrier to the provision of home infusions was that of insufficient funding. Other problems included unclear patient selection criteria and hand over issues/poor communication (Table 3.20).

Table 3.20, Trust Questionnaire, Barriers to Providing HTHH

Barriers to providing HTHH	Number of comments
financial	26
Transport/geographical	7
Lack of trained staff/facilities	7
Patient, carer, home not happy or suitable	6
None	6
Lack of co-ordination/communication	5
Timeliness	3
Lack of awareness of HTHH	3

3.2.4.2.17 Reason Trust provides HTHH

The answers to this question are shown in Figure 3.18. The other reasons and further comments given in answer to this question are given in Table 3.12.

Figure 3.18: Trust Questionnaire, Reason Trust Provides HTHH

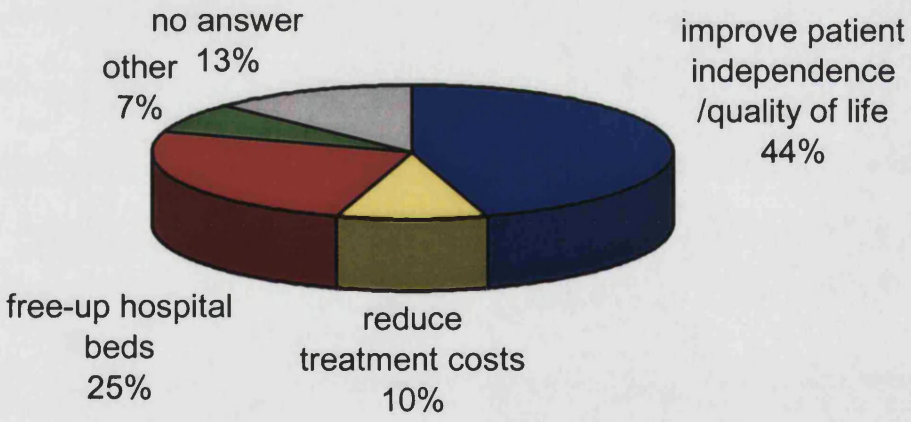


Table 3.21: Other Reasons Trust Provides HTHH, Trust Questionnaire

Survey no	Specify other reasons	Further comments
1	It has to (all of the above)	
28	reduce patient stay, therefore reduce risk of hospital acquired infection	
90	Cancer patients are dying and receive chemo at home for palliative reasons	
98		essential that children can start to lead some kind of normal life - attend school, play with other children (not in hospital setting) brothers and sisters.
124		This is the current reason. Some of the other categories may also become relevant later in the year.
222		Give patients sense of dignity - feel they are helping themselves not reliant on nurses all the time
227	Patient able to stay at home with family.	
244	to treat people with long term IV requirement	
258	recommended treatment for their type of cancer.	
261	better clinical outcome	for 5FU patients
271	Benefit of infusional chemotherapy in response rates and survival.	
322		All of the above apply but very often it is initiated by the patients who request the option of home care.
323	for paed's, to avoid patient coming in to hospital in the first place to reduce exposure to hospital environment.	
344	I for TPN and f for cytos	
373	when patient is too ill to attend outpatient clinic for chemotherapy	

3.2.4.2.18 Collaboration with the Health Authority Prescribing Team

Is there any collaboration between the Trust and the Prescribing Team (e.g. Pharmaceutical Adviser) on issues regarding HTHH?

30 of the 94 Trusts (31.9%) said that there was some collaboration. This varied from limited contact regarding contracts or the cost of therapy to regular update meetings and clinical case conferences. The responses given are shown in Table 3.22. This also includes comments from the 38 Trusts who said they had no contact and 26 who did not answer or gave other answers to the question such as "don't know".

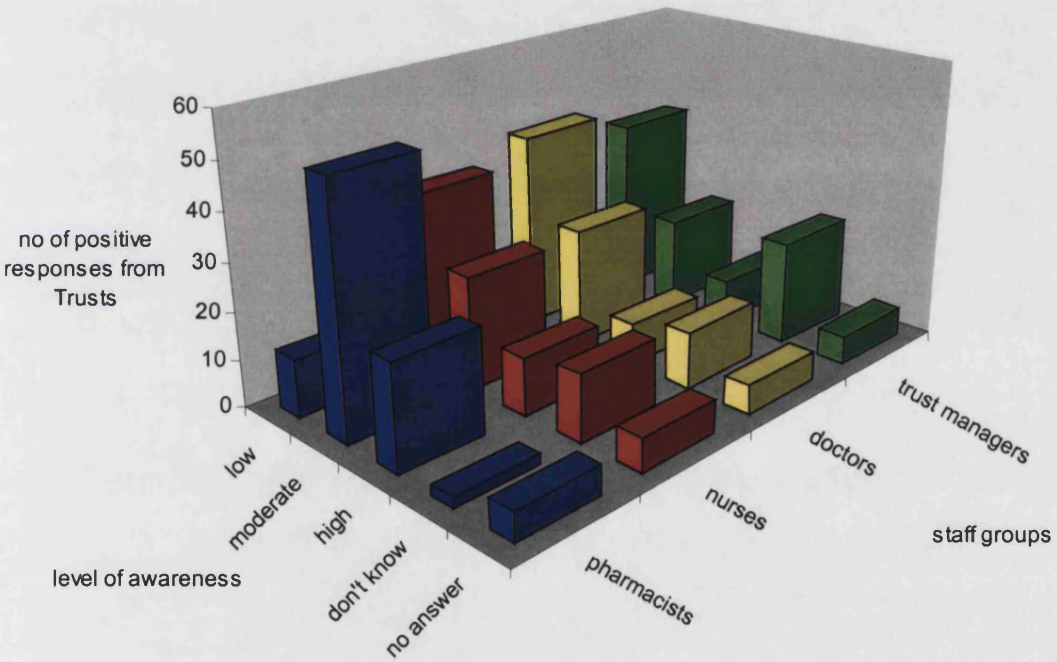
Table 3.22: Collaboration with Health Authority Prescribing Team

Survey no	collaboration with HA?	comments
96	yes	we are attempting to understand the current situation, a precursor to monitoring and standard setting.
212	yes	discussion of costs
180	yes	I think so, as the business manager has regular meetings with the purchasers.
3	yes	contracts for TPN at home provision
165	yes	There is informal contact between the HA pharmaceutical adviser and the hospital pharmacists.
123	yes	HAs sometimes have contract with alternate Home care company and do not want to use our major supplier. Have tried to persuade them to use our main supplier.
219	yes	with HA contracts manager to maximise use of resources, with HA Prescribing Adviser - co-supervision of home care MPhil project
117	yes	specify type of supplier i.e. licensed unit
194	yes	to agree provision of health care at home and obtain funding from the HA to go ahead.
92	yes	collaboration between Trust and HIV purchasers at HA
74	yes	shared care protocols are currently being developed
72	yes	regular update meetings clinical case conferences
37	yes	limited telephone contact
28	yes	communication when problems arise e.g. dealing with EL(95)5, high cost drugs
12	yes	mainly between directorate business managers and the Health Authority
118	yes	The PA of the HA the patient lives in is always contacted and treatment discussed before pt sent home on therapy (include in contracting process)
321	yes	Membership of prescribing committee
227	yes	sort of
368	yes	advice available from a pharmaceutical adviser
337	yes	Purchasers are consulted prior to patient discharge since they are charged for services directed from this Trust.
244	yes	previously
322	yes	In some Has there is collaboration with the pharmaceutical adviser in setting up contracts with the commercial companies.
283	yes	Discussion on patient by patient basis, e.g. funding
287	yes	to sort out funding only
172	yes	Only in the initial set up period for individual patients.
223	yes	adviser is aware of current level and would be contacted by me re any specific issues/new service requirements
323	no	At the initiation of secondary care responsibility post EL(95)5 there was collaboration. Since then no further money allocated by main HA and not considered relevant for HA prescribing team.
100	no	Our patients are from the whole of the UK which makes this very difficult.
116,,230, 282,258,66,53, 98,222, 344, 349	No, none, don't know, not yet, uncertain, ?	

3.2.4.2.19 General Level of Awareness of HTHH Amongst Staff Groups

The pharmacists were asked for their opinion of what was the general level of awareness of HTHH amongst various staff groups. The answers are shown in Figure 3.19. Generally other professions were thought to have a fairly low awareness and pharmacists a moderate level of awareness. There were some comments that specialist nurses or doctors working on units where patients were treated at home had a high level of awareness whereas a much lower level of awareness was the norm.

Figure 3.19: Trust Questionnaire, General Level of Awareness of HTHH amongst Staff Groups



At the end of the questionnaire there was an opportunity for the hospital pharmacists to make further comments regarding HTHH. The comments received are shown in Appendix 24. These were coded with the other qualitative data as described in Section 3.2.3.4.2 and the results incorporated into the coding frame (Appendix 20).

3.2.4.3 Commercial Home Care Company Survey

3.2.4.3.1 Response Rate

All six commercial providers of home infusions replied to the questionnaire survey giving a response rate of 100%. The data was collected over the time period November 1998- January 1999.

3.2.4.3.2 Which aspects of care does your company provide?

Five provide an entire package of care to patients at home under EL(95)5 [41] and the other provides the entire package of care jointly with a hospital or other organisation.

All six of the commercial providers directly provide equipment such as refrigerators and pumps, disposables, delivery to the patient's home, a 24-hour help line, training of the patient/carer and education for other health care professionals. Other services were, in some cases, either subcontracted or provided by a hospital or other organisation.

Three companies provide their own nurses, two have some company nurses and also subcontract and one of these also said that the hospital or other organisation sometimes provides. One company subcontracts for all of the nursing care provided.

Three companies do their own aseptic reconstitution/filling of infusion devices whilst two subcontract this. One company said that the hospital or other organisation provides this part of the service.

One company subcontracts waste disposal and the others do it themselves. The company maintains infusion pumps themselves in four cases, one subcontracts this work and the other company said that the hospital or other organisation provides this service.

The only other service specified was company generation of custom compiled management reports.

3.2.4.3.3 Number of treatment doses per week supplied?

Three companies provide more than 120 treatment doses per week, two provide between 30 and 60 treatment doses and one provides between 10 and 30 treatment doses per week.

3.2.4.3.4 Treatment Supplied

The only two treatments that all six companies were providing at the time of the survey was home TPN and desferrioxamine infusions for thalassaemia (Table 3.23).

Table 3.23: Indications for which commercial providers are supplying HTHH

	currently provide	have provided in past	have never provided	may provide in the future
intravenous antibiotics for cystic fibrosis patients	4	2	0	0
intravenous chemotherapy agents for patients with cancer	5	1	0	0
intravenous anti-infectives for HIV patients	5	1	0	0
total parenteral nutrition (TPN)	6	0	0	0
intravenous desferrioxamine for Thallasaemics	6	0	0	0
continuous intravenous anticoagulant treatment	1	1	0	4
intravenous antibiotics for other conditions	4	1	0	1
intravenous terbutaline for asthma	2	0	3	1
intravenous prostacyclin	1	1	2	3
intravenous immunoglobulins	2	1	0	3
subcutaneous beta-interferon	1	0	1	4
enzyme replacement for Gaucher's disease	2	0	1	2
intrathecal baclofen (for relief of spasticity as a result of spinal cord disease)	0	0	2	4
intravenous calcium gluconate infusions (for ricketts)	0	1	1	4
methotrexate for arthritis	2	0	2	3
Other Factor VIII Growth hormone Fertility treatments Pain relief				

3.2.4.3.5 How many Health Authorities/Trusts do you currently have contracts with?

Table 3.24 shows the number of contracts that commercial providers have with HAs and Trusts. One company stated that all of their contracts were with hospitals not HAs. Two others made the point that contracts are often on an individual patient basis Box 1.

Table 3.24 How many HA/Trusts do you currently have contracts with?

Range	Health Authorities	Trusts
	Number of companies giving answer	
1-3	2	0
4-7	0	2
8-11	1	1
12-20	0	0
>20	1	2

Box 1

"Virtually all of our business is non-contractual (N.B. Often patients are tendered for individually but in a non-formal fashion i.e. hospitals ring for quotes and usually go for the cheapest!)."

"Only one formal Health Authority contract, others are per named patient. Contracts at Trusts normally per named patient."

3.2.4.3.6 Who sets service specifications?

All six companies stated that Trusts set service specifications. Two companies just mentioned Trusts, three said HAs and Trusts, and one said HA, Trust and NHS supplies in conjunction with the HAs and Trusts.

3.2.4.3.7 Audit Systems

The audit systems that the commercial providers were aware of put in place by HAs or NHS Trusts with whom they have contracts are shown below in Figure 3.20 and details of these systems are shown in Table 3.25.

Figure 3.20: Commercial Home Care Company Questionnaire, Are You Aware Of Any HA Or NHS Trust With Whom You Have A Contract Having An Audit System in Place?

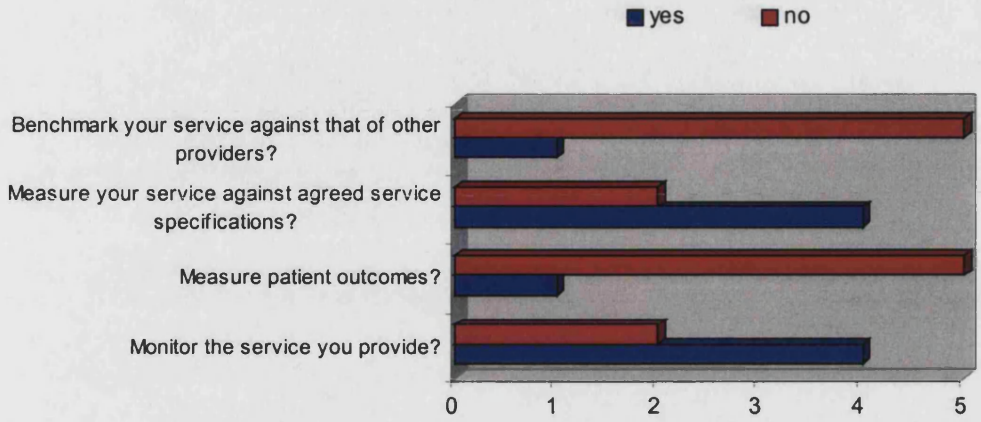


Table 3.25: Details of Audit Systems

Survey no	Details of audit systems.
1	Monitor -quarterly review meetings on service performance.
2	Quarterly reviews are undertaken with a number of customers to ensure our service continues to meet the agreed standards. We are constantly compared with our competitors, there are a number of Health Authority and Trusts who will have patients on different home delivery systems in order to compare both costs and standards.
3	The audit systems we have in place with HAs and Trusts have all been initiated by our company. In our opinion many companies, particularly those using Agency nurses, provide sub-optimal care and we would like to differentiate ourselves on quality grounds
5	We hold quarterly review meetings. We have just carried out a patient satisfaction survey for our cystic fibrosis patients. We are in the process of setting up a customer care pathway for TPN.

3.2.5 Discussion

3.2.5.1 Response Rate

A better response rate was achieved to the commercial home care company questionnaire (100%) and HA questionnaire (87%) than the Trust questionnaire (56%). This may be due to the fact that one mailing with one reminder letter was sent out to the Trusts but non-responders to the Health Authority survey received both written and telephone reminders on up to 5 occasions. It may also have helped that the HA questionnaire was in most cases distributed personally by the researcher with some sort of presentation or explanation of the objectives of the project. It was easier to follow up non-responders to the commercial home care company questionnaire than the others because of the small numbers involved. Two companies helped to design the questionnaire and the researcher explained the aim of the surveys to the commercial providers by telephone or in person to the others.

Both the HA and Trust surveys produced a response in approximately equal number from all the regions (Figure 3.21), allowing for the fact that some regions are larger than others. For the HA survey the range was 71% (Anglia and Oxford) to100% (South and West) of questionnaires returned. The figure was lower for the Trusts for the reasons discussed above ranging from 35% (Northern and Yorkshire) to 74% (South and West), (Figure 3.22). It may be in areas such as the Anglia and Oxford where the response rate from HAs was relatively low and that from the Trusts relatively high that responsibility for HTHH has been passed to the Trusts and therefore the Pharmaceutical Advisers knew little about the HTHH being provided (see Section 3.2.5.1.2) whereas the hospital pharmacists knew more and were therefore more likely to complete the questionnaire.

The largest numbers of responses were received from HAs in the North West region and Trusts in the North Thames and North West regions. These were also the regions which had the largest numbers of HTHH patients (Section 3.2.5.1.2.). The largest proportion of both HAs and Trusts responding to the questionnaire

were from the South and West region. This may have been due to the fact that the research was being conducted from within the region.

Figure 3.21*:* Number of Responses by Region

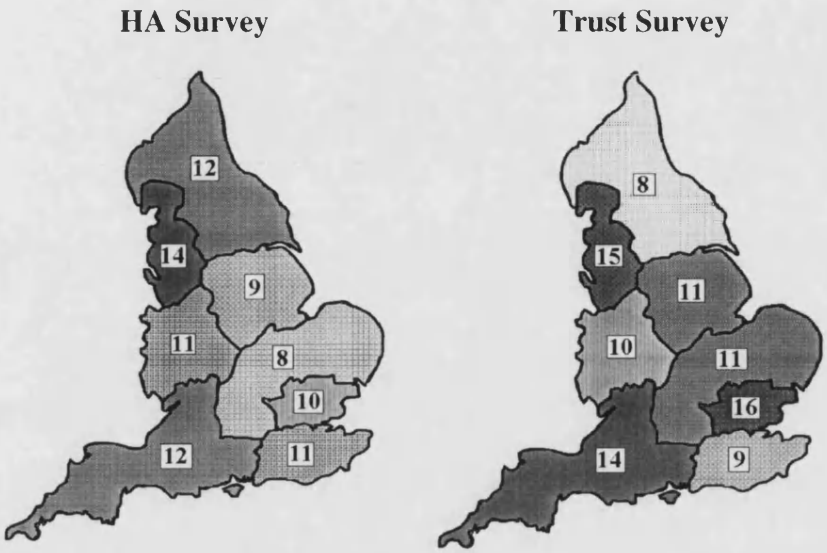
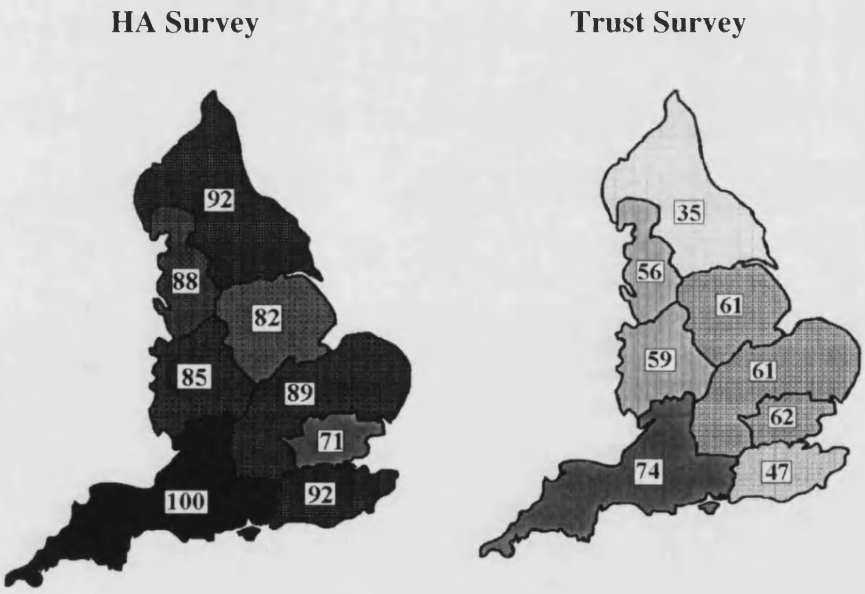


Figure 3.22: Percentage Response Rate by Region



3.2.5.1.1 Bias

3.2.5.1.1.1 Sample Bias

There was no sample bias to be taken into account, as in all three surveys the entire populations were included.

3.2.5.1.1.2 Response Bias

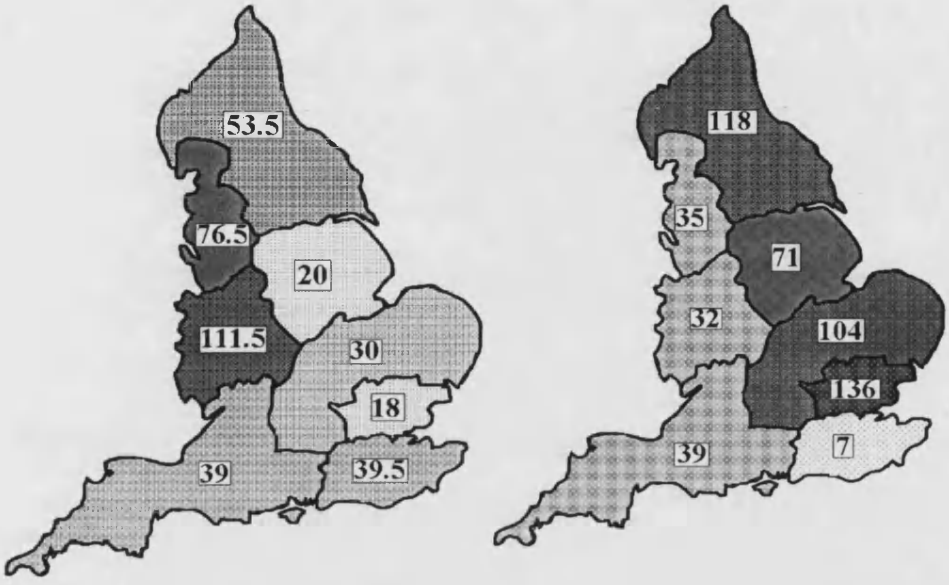
There was no response bias in the commercial home care company survey as a 100% response rate was achieved. There may have been some response bias in the HA survey and this is discussed in Section 2.2.6.1.1. It is important when interpreting the data collected from the Trust survey that the possible effects of response bias are taken into account. It could be that non-responders found the questionnaire difficult to complete because of their limited experience of HTHH. Care is therefore needed when extrapolating data obtained from the questionnaire. It is also worth noting that a non-response from one of the major tertiary centres providing HTHH for a large number of patients may skew the data in the other direction when it is extrapolated.

3.2.5.1.2 Geographical Distribution

Data from both HAs and Trusts were grouped by region so identification of individual HAs and Trust would not be possible and then plotted on a map to show the geographical distribution of the provision of HTHH (Figure 3.23).

The geographical distribution of patients receiving home infusions would be expected to be more accurate from the HA questionnaire than from the Trust questionnaire as the HA would pay for home infusions for all patients under it's jurisdiction whereas the Trust data would be skewed by the presence of tertiary centres. This can be seen to be the case for home TPN (Figure 3.23e). Of the 93 home TPN patients in the North Thames region 65 were from one Trust and of the 92 in the North West region 84 were from one Trust. It is known that these are two large tertiary centres.

Figure 3.23a: Actual Number of Cystic Fibrosis Patients Receiving Intravenous Antibiotics

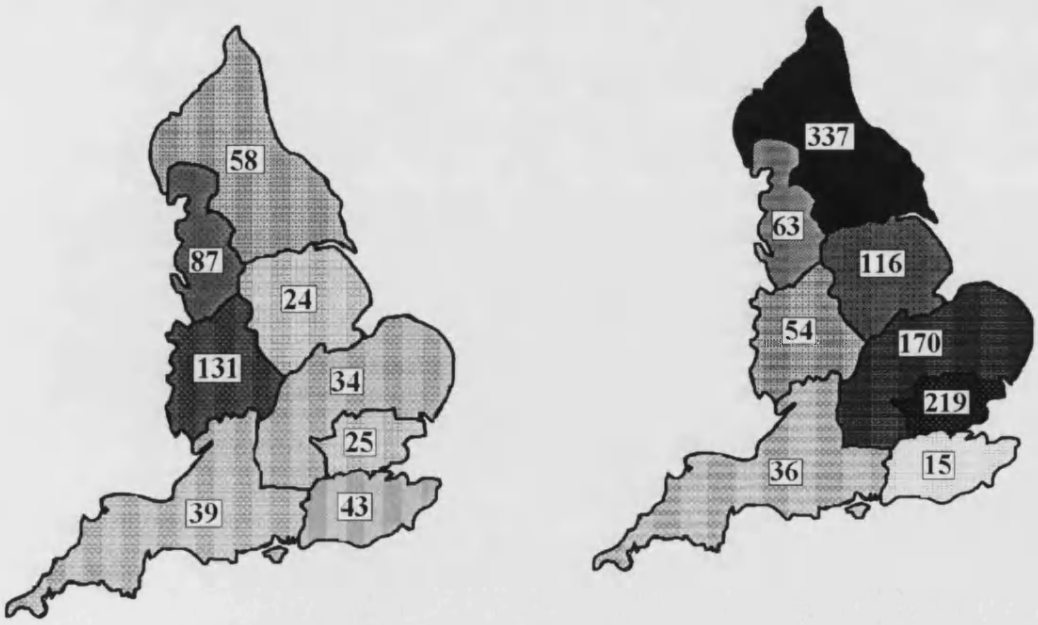


HA Survey

Trust Survey

Figure 3.23b - Number Of Patients Receiving Intravenous Antibiotics For Cystic Fibrosis Normalised*

***divided by % response rate from region multiplied by 100**



HA Survey

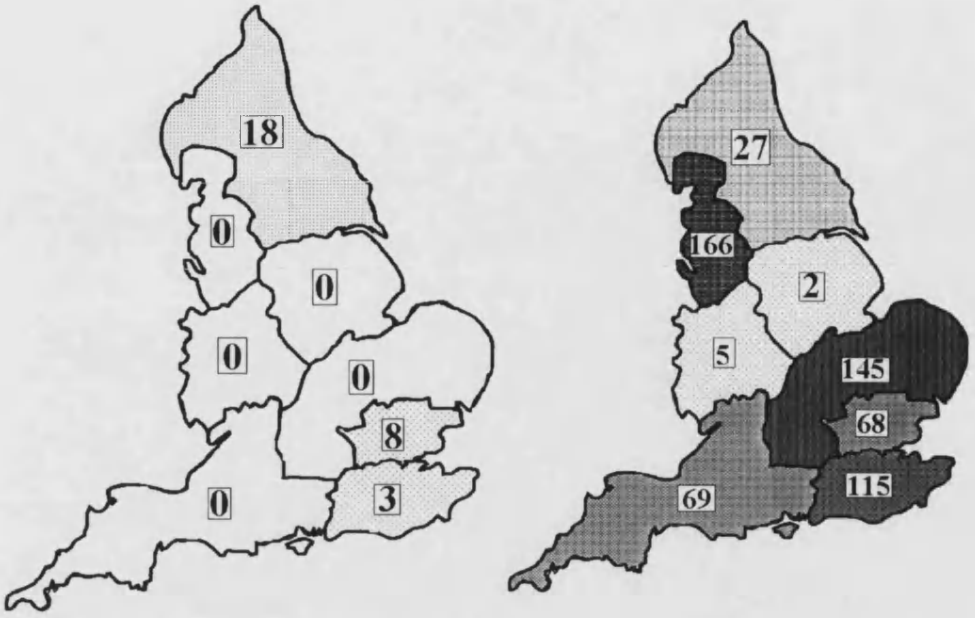
Trust Survey

When considering these data it must be remembered that both cystic fibrosis and thalassaemia are hereditary conditions and the incidence in the population may not be the same around the country. The incidence of HIV is also not evenly distributed geographically [274]. The incidence in the North Thames and South Thames regions accounts for more than 70% of the incidence in the whole of England. Accurate demographic data of this kind is difficult to obtain and would be necessary before any firm conclusions could be reached.

It can be seen from Figure 3.23a and b that the numbers of patients being treated with home antibiotic infusions for cystic fibrosis, reported by the Trusts were much higher than those from the HAs for the Northern and Yorkshire, Trent, Anglia and Oxford and Northern and Yorkshire regions but the reverse was true for the North West, West Midlands and South Thames regions. This is possibly due to the fact that Trusts were choosing to treat and fund patients with home infusions in the first case whereas the HAs are purchasing care for these patients under EL(95)5 [41] in the second case. Demographics of the areas must be taken into account. A study in the South and West region reported that there were 664 patients with cystic fibrosis receiving care within the region and a further estimated 53 patients living in the region but receiving care outside at 31st December 1995 [275]. This would mean that in the South and West region approximately 5% of all cystic fibrosis sufferers were receiving home antibiotic infusions.

In all cases the numbers of patients being treated with home chemotherapy infusions was larger from the Trust survey than from the HA survey. This was substantially so in most cases. There were very few patients receiving home chemotherapy infusions whose care was being purchased through the HA. It appears from these data that patients in the West Midlands and Trent regions are less likely to receive their chemotherapy at home than those in areas such as the North West, Anglia and Oxford and South Thames. Five of the eight regions had no HAs purchasing home chemotherapy infusions.

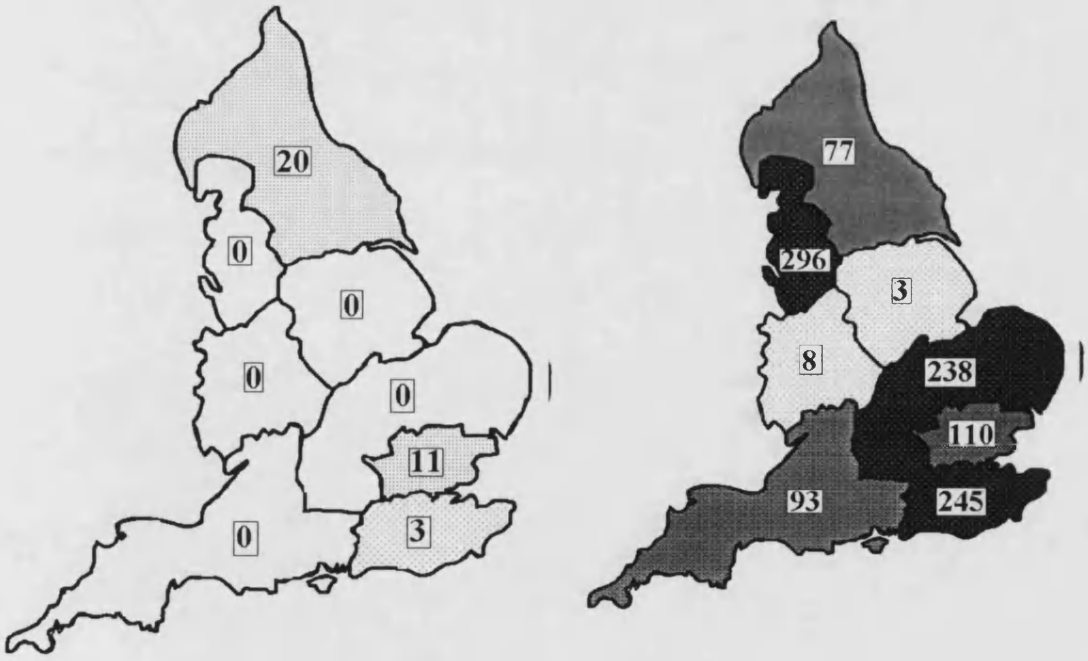
Figure 3.23c - **Actual Number of Home Chemotherapy Infusions**



HA Survey **Trust Survey**

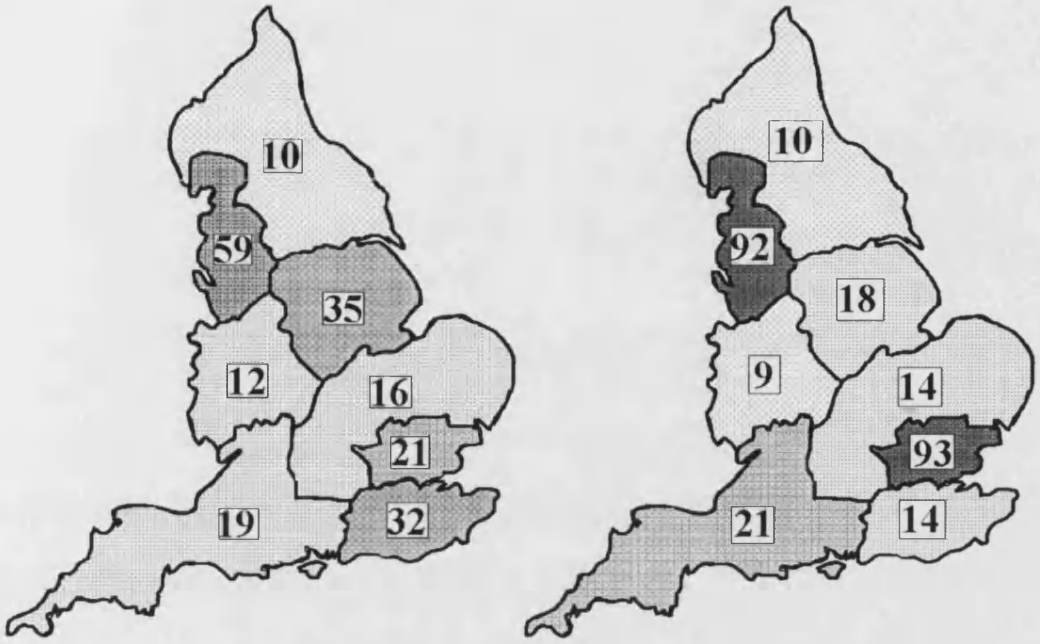
Figure 3.23d - **Number of Home Chemotherapy Infusions Normalised***

***divided by % response rate from region multiplied by 100**



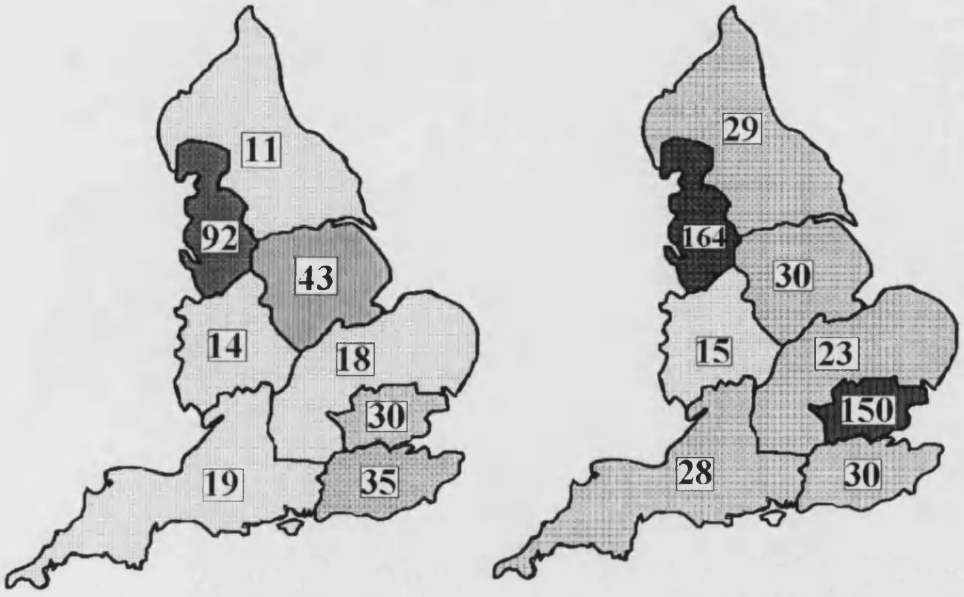
HA Survey **Trust Survey**

Figure 3.23e - **Actual number of Patients Receiving Home TPN**



HA Survey **Trust Survey**

Figure 4.22f - Number of Patients receiving Home TPN Normalised*
***divided by % response rate from region multiplied by 100**



HA Survey **Trust Survey**

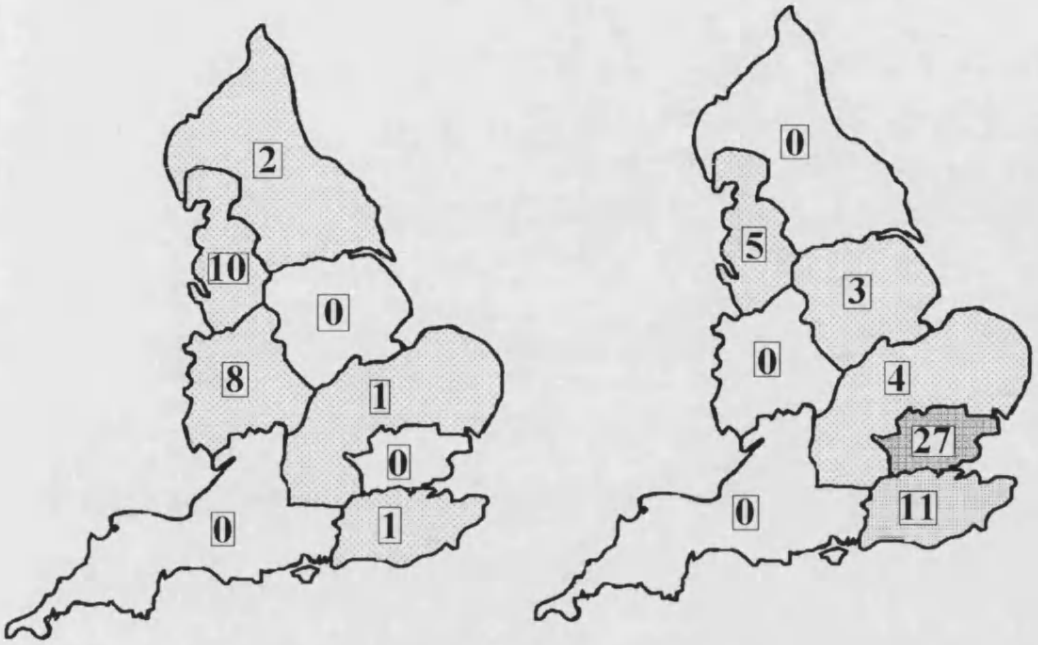
There was slightly more correlation between the figures received from the HA and Trust survey on the numbers of patients receiving home TPN. The geographical distribution from the Trust survey is skewed as previously discussed by tertiary centres. This could account for the difference between the HA and Trust figures for the North West and North Thames regions. More HAs were responsible for contracting for TPN under EL(95)5 [41] than for other home infusions. In two instances the number of patients was larger from the HAs than the Trusts suggesting that care is being purchased by the HAs directly from commercial providers.

As would be expected the largest densities of population of HIV patients were around London, the North and South Thames regions. It appears that in the West Midlands and Northern and Yorkshire regions all of these infusions for HIV are purchased by the HA. However in South Thames and North Thames the Trusts are responsible for arranging care for nearly all of the patients.

In most cases the number of patients receiving home infusions of desferrioxamine was larger from the Trusts survey than the HA survey. By far the largest numbers of patients were in the North Thames region and this is probably due to the immigrant population in this area.

There were seven Trusts who said that there were geographical or transport barriers to the provision of HTHH. This was a particular problem in rural areas where patients live a long way from the hospital but although the provision of high quality HTHH is more difficult in these areas it is precisely the patients who live many miles away from the nearest hospital who can ultimately benefit more from the availability of home treatment. It enables them to keep in regular contact with their friends and family and does not mean that extra strain is put on the family by a carer having to travel many miles or stay away from home whilst the patient is in hospital.

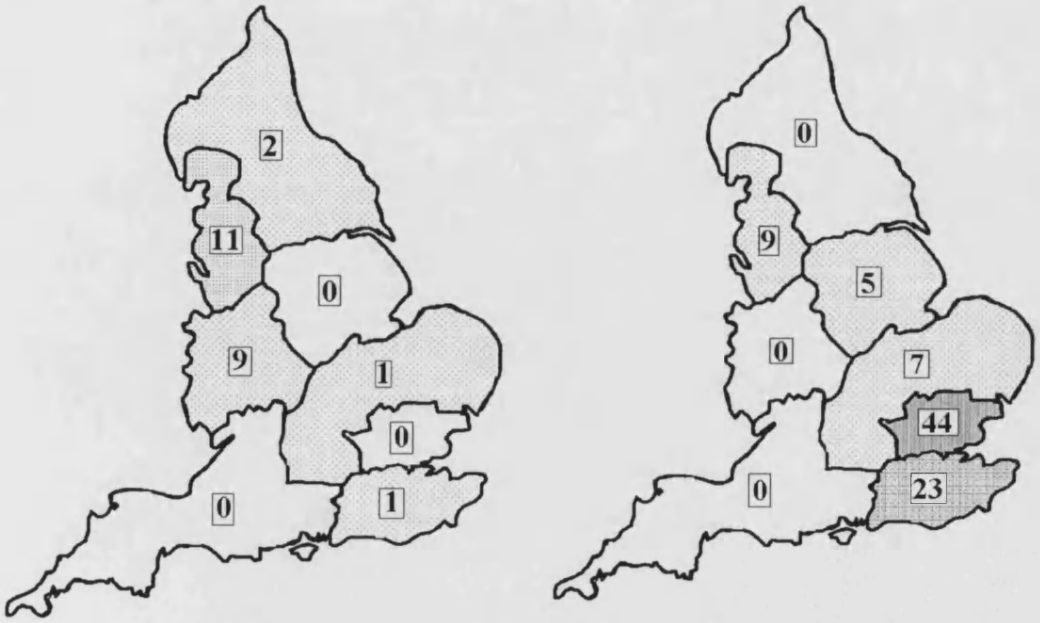
Figure 3.23g - Actual Number of Patients Receiving Home Infusions for HIV



HA Survey **Trust Survey**

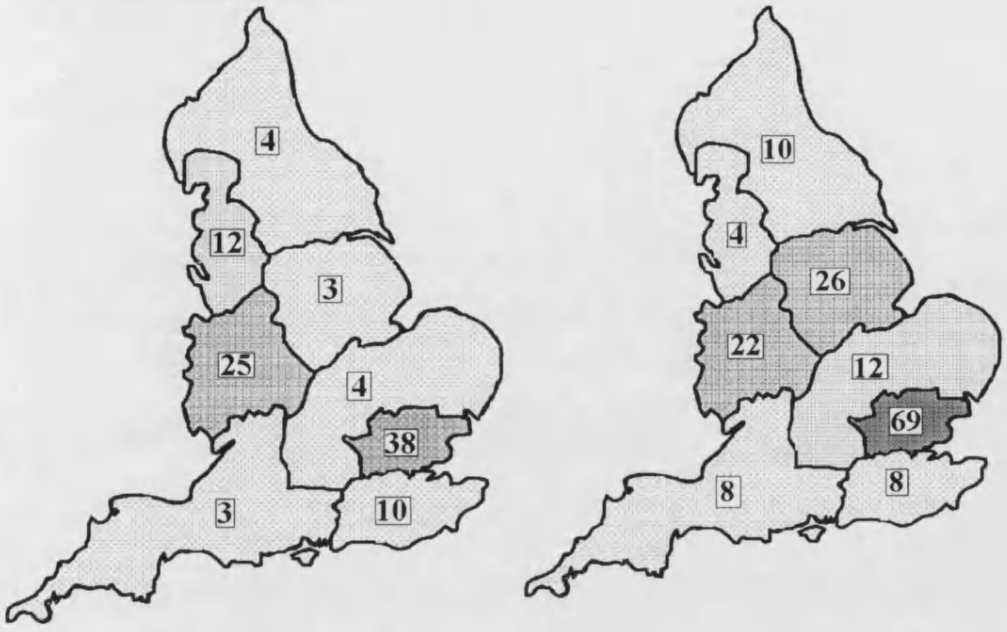
Figure 3.23h - Number of Patients Receiving Home Antiviral Infusions for HIV Normalised*

***divided by % response rate from region multiplied by 100**



HA Survey **Trust Survey**

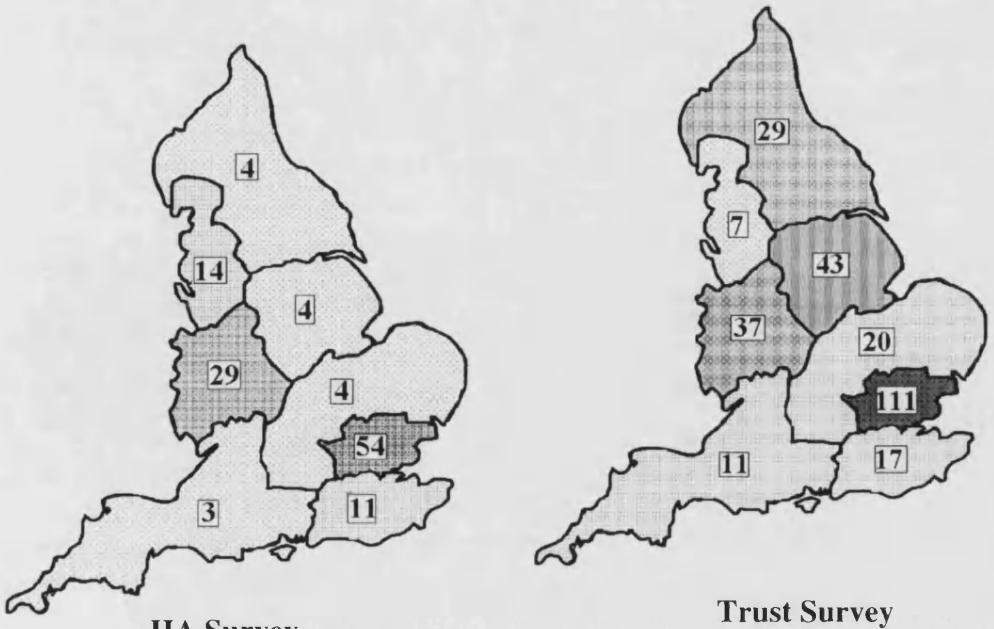
Figure 3.23i- Actual Number of Thalassaemics Receiving Home Desferrioxamine Infusions



HA Survey Trust Survey

Figure 3.23j - Number of Thalassaemics Receiving Home Desferrioxamine Infusions Normalised*

***divided by % response rate from region multiplied by 100**



HA Survey Trust Survey

3.2.5.1.3 Proportion Of Trusts And HAs Unable To Provide Answers Re HTHH Patients

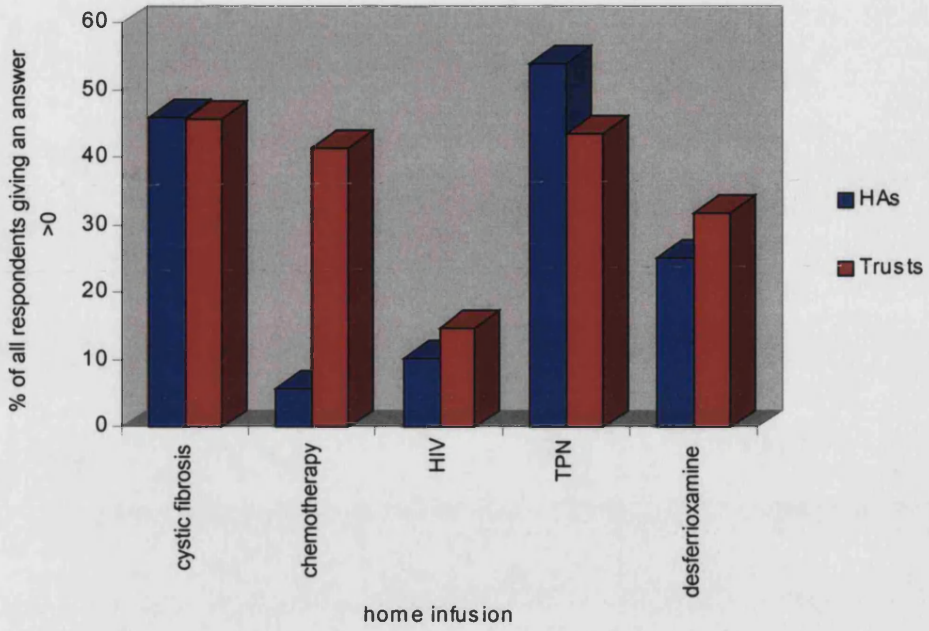
In many cases neither the Trusts nor the HA were able to specify the number of patients receiving HTHH. While the HA may take on responsibility for contracting for the provision of, for example, HPN for the patients in their area they may leave the provision of other home infusions such as chemotherapy or desferrioxamine entirely to the local Trust, this can be seen from the data in Section 3.2.5.1.2. The HA may not even be aware that patients are being treated at home with other such infusions.

It was not easy to interpret the answers regarding numbers of patients from the questionnaires. When the question was left blank it could mean that no patients were being treated at home with that drug or for that condition, but equally it could mean that the responder did not know if there were any of these patients. It is difficult to distinguish at times between home patients and outpatients. A patient may receive therapy as an inpatient, outpatient and home patient at different times and therefore the numbers of patients can be difficult to estimate. This is also compounded by the fact that the number of patients receiving home infusions is never a static number. It should also be noted that the questionnaire may not have been targeted at the most appropriate person in the HA or Trust and for this reason answers may not have been obtained.

3.2.5.1.4 Proportion Of HAs/Trusts Providing Various Home Infusions

Figure 3.2 shows the proportion of HAs and Trusts providing HTHH for various indications. It is striking that the proportion of Trusts providing home chemotherapy infusions is far larger than the HAs. These data would be in line with the assumption that the HAs are only purchasing those home infusions previously prescribed on FP10. It is unlikely that GPs were prescribing home chemotherapy infusions prior to EL(95)5 [41] and therefore EL(95)5 [41] did not affect the purchasing of this service.

Figure 3.24: Proportion of HAs and Trusts Providing Various Home Infusions



The proportion of HAs purchasing HTHH (shown in Figure 3.3) differed from the results obtained in a telephone survey conducted by The Medicines Management Unit, Keele University [42]. This study asked whether packages of care were being purchased under EL(95)5 [41] for TPN, intravenous chemotherapy and intravenous antibiotics for cystic fibrosis. The proportion of HAs who said they purchased care for these patients were 92%, 37% and 81% respectively (cf. 54%, 6% and 46% in this survey). The survey was conducted over a period of 6-12 months before the data from this survey was collected.

The researchers at Keele wrote to the HA Chief Executive asking who was the most appropriate person to contact regarding the provision of HTHH under EL(95)5 [41]. Pharmaceutical, Medical Advisers and Contracts Managers were the most common people cited, suggesting that this survey was aimed at the same people within the HAs. The Keele survey only asked whether the HA purchased hi-tech packages of care for the indications specified whereas this survey asked for an approximate number of patients under the care of the HA currently receiving HTHH in accordance with EL(95)5 [41] for the specified indications. Fewer HAs were able to answer the question regarding numbers and this may account for some of the difference in the results obtained. It could be argued that

a written response that a person had time to look up the answers to might be more accurate than an off the top of the head response to a telephone survey. It may also be that there is much confusion within HAs as to what is covered by EL(95)5 [41] and exactly what the HA is purchasing from whom and for how many patients. This is consistent with the fact that monitoring of provision of HTHH is poor, as there is poor understanding of whose responsibility this is (see Section 3.2.5.2.5).

3.2.5.1.5 Numbers of Patients receiving HTHH

The total numbers of patients receiving the various types of HTHH are shown in Table 3.26. The numbers obtained from a Monopolies and Mergers Commission report investigating a proposed merger between Fresenius and Caremark, two commercial HTHH providers, are also shown. These were an estimate of the current home care market in the whole of the United Kingdom, mostly obtained from commercial providers and are discussed in Section 3.2.5.1.6

Table 3.26: Numbers Of Patients Receiving HTHH

	Health Authority Survey (England)		**Trust Survey (England)**		***Monopolies & Mergers Commission report data for 1997 [43] (UK)***
	actual	normalised*	actual	normalised**	
Antibiotics for cystic fibrosis	388	446	530	879	*908 (all antibiotic infusions)*
Chemotherapy infusions	29	33	597	990	*490*
Antivirals for HIV	22	25	50	83	*283*
Home TPN	204	234	271	449	*322*
Desferrioxamine	99	114	159	264	*450*
Enzymes for Gaucher's disease	11	13	6	10	*94*

*divided by 87 multiplied by 100

** 167-11 who did not provide HTHH = 156 94/156=60.3%, therefore divided by 60.3 multiplied by 100, does not take into account the fact that some non-responders may not provide HTHH

**Not accurate to normalise numbers from Trust survey because they include tertiary providers with very large numbers of patients.

If the proportion of HAs purchasing HTHH from the Keele study [42] are accurate then these numbers will be significantly underestimating the true

numbers. It is still not possible from these data to determine accurately the total number of patients who are receiving HTHH in England. In some cases the HAs contract for the service themselves and were able to give accurate numbers of patients, under their care, for whom they purchase HTHH. In this case the Trust and/or commercial supplier will have also included these patients in the responses to their questionnaire. In other cases the Health Authority have little or no idea of the numbers of patients in their area receiving HTHH. These patients will also be accounted for in the responses from providers. There is no co-ordinated approach to providing home infusions and therefore obtaining accurate information on the numbers of patients is almost impossible. If the NHS have no idea how many patients are being treated and how much is being spent on HTHH at any point in time it seems unlikely that they are aware of the cost effectiveness and quality of the care being provided (see sections 3.2.5.2.2 and 3.2.5.2.5).

3.2.5.1.5.1 Correlation Between HA, Trust and Commercial Home Care Company Surveys – Number of Patients

The largest numbers of patients being treated at home according to the Health Authorities were cystic fibrosis patients receiving antibiotics but the results from the Trust survey show that the largest numbers according to the hospitals are receiving infusions of chemotherapy (Figure 3.25). This is probably because the HAs do not fund home chemotherapy under EL(95)5 [41], as prior to 1995 the Trusts and not the GPs were supplying patients so there was no money for this to top-slice from GP prescribing budgets. In 5 out of the 8 regions none of the HAs said they had any home chemotherapy patients (Figure 3.23c). This highlights one of the problems with the provision of HTHH in England under EL(95)5 [41]. Health Authorities were only able to use money top-sliced from GP prescribing budgets to purchase HTHH and therefore any HTHH that was not being prescribed by GPs is not included in the Health Authority contracts.

Figure 3.25a: Actual Numbers of Patients Being Treated with Home Infusions (Response from 87% HAs and 60% Trusts)

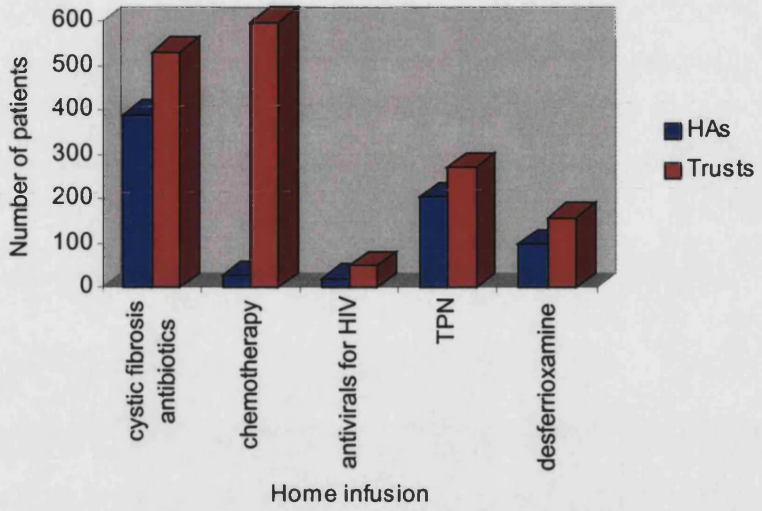
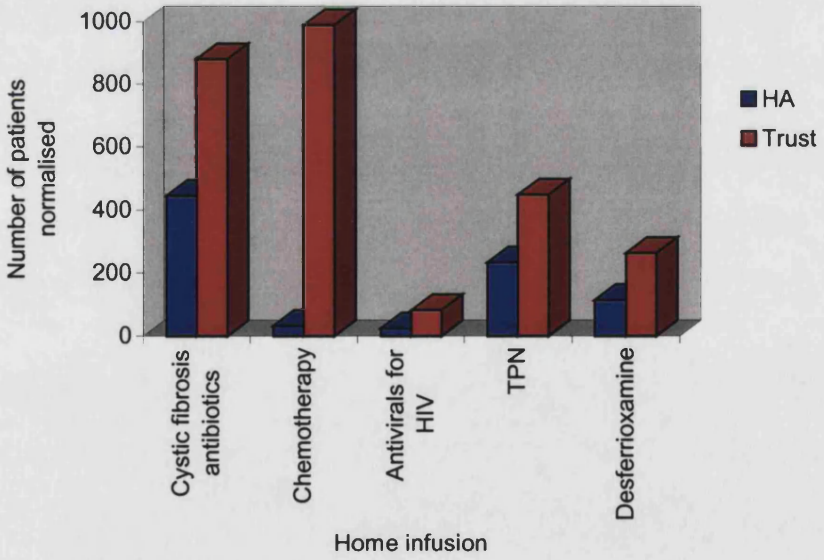


Figure 3.25b: Numbers of Patients Being Treated with Home Infusions Normalised



In all but one region the total number of patients receiving home infusions was larger from the Trust survey than from the HA survey. This supports the finding that Trusts are providing HTHH which is not being funded for and purchased by the HA under EL(95)5 [41]. In appears that in the West Midlands the HAs must

be contracting directly with commercial providers for many of their patients. In this region it is only home chemotherapy infusions where the number of patients specified by the Trusts is greater than those specified by the HAs (Figure 3.23c).

The discrepancy between the numbers of patients being treated by Trusts and the numbers given by the HAs show that although some packages of care are being purchased for patients through the HAs, there are also many patients being treated with home infusions whose therapy is being paid for out of Trust funds. This poses further questions such as

a) Is the quality of care the same for both groups of patients?
b) Why are these packages of care all not being purchased through the same contract, as there may be economies of scale in purchasing in this way?
c) Why are HAs not purchasing packages of care for all patients covered by EL(95)5?
d) Has EL(95)5 caused inequity of care?

Due to the nature of the therapies used and conditions treated with home infusions many of the patients were under the care of hospital doctors on 1st April 1995 and hence receiving their therapy through arrangements made by the Trusts. It seems absurd that the purchasing of HTHH by HAs is based on whether the GP was willing or not willing to take on prescribing for home infusions prior to 1995. The introduction of a single mechanism of purchasing and providing care for home infusion patients would seem a sensible approach.

From the synthesis of these data it appears that the Trusts are choosing to treat patients with home infusions which are not covered by HA contracts. This is also apparent from the other therapies being administered in the domicillary setting that were specified by Trusts but not by HAs (Section 3.2.5.1.6.1). The data from the Monopolies and Mergers Commission Report [43] supports this showing that the NHS provides the following percentages of the home care market in 1997 HPN 14%, antibiotics 50%, antivirals 76%, chelation 75%, chemotherapy 77% and immunoglobulins, Gaucher's disease, infertility and beta interferon 0%.

3.2.5.1.6 Validation Of Data With That Obtained From Other Sources

These data correlated broadly with those obtained from other sources for antibiotics and HPN. The Monopolies and Mergers Commission report [276] on the proposed Fresenius, Caremark merger estimated from information received from commercial providers that 908 patients were receiving home antibiotic infusions in the UK in 1997 (Table 3.26). This compares with an estimate of 879 for England from the Trusts survey, just for cystic fibrosis patients.

The 1997 Annual Report of BANS [277] estimated, "from incomplete information" that there were 250-360 patients receiving home TPN at the time of their survey. The British Association of Parenteral and Enteral Nutrition (BAPEN) estimated in 1994 [278] that there were between 250 and 300 patients receiving home TPN. The Monopolies and Mergers Commission gave an estimate of 322 patients in 1997. This compares with 449 (just in England) extrapolated from the data collected from the survey of Trusts or 234 extrapolated from the HA survey. The reason for slightly larger numbers of this survey could be that a few Trust pharmacists might have included numbers of inpatients in their response. It was stressed during the telephone survey, in the accompanying letter and in the questionnaire itself that information was required only on home infusions.

The numbers for the North West region for the Health Authority survey are higher then those reported by Pilling [6]. In his report carried out a year earlier than this survey, 1995, the number of individual patient contracts for TPN, IV antibiotics, IV antivirals, IV chemotherapy and desferrioxamine were approximately 54, 55, 12, 8 and 2 respectively versus 59, 77 (just cystic fibrosis), 10, 0 and 12 respectively from the 14 HAs in the North West region who completed this survey.

It appears from the commercial home care company survey that hospital Trusts commission most HTHH services from them. This is supported by the Trust survey but not by the HA survey.

3.2.5.1.6.1 Other Home Infusions

The lists of other home therapies obtained from the three surveys it can be seen were very similar (Table 3.27). The Trusts listed infusions such as apomorphine, dopamine and aminophylline which were not mentioned by the HAs or commercial home care companies. EL(95)5 [41] has been interpreted differently by different Trusts and HAs. It can be seen from these data that some include all of these other therapies as being covered under the EL and others include some or all of the examples listed in EL(95)5 [41]. This is also shown by the fact that 5 HAs have patients being treated at home with enzymes for Gaucher's disease, not mentioned in EL(95)5 [41], whereas many Trusts are independently funding patients with home chemotherapy or antivirals for HIV, specified in EL(95)5 [41] but not covered by Health Authority contracts.

Table 3.27: Other Home Infusions Being Provided

HA, Trust and CHCC	Trust and CHCC	Trust and HA	HA and CHCC
Enzymes for Gaucher's Disease, Immunoglobulins, Terbutaline, Prostacyclin	Antibiotics for other indications, Pain relief, Methotrexate	Continuous ambulatory peritoneal dialysis	Beta interferon
HA Only	**Trust Only**	**CHCC Only**	
Calcium gluconate, Enteral feeding, Intrathecal baclofen	Antivirals for transplant patients, G-CSF, Magnesium, Home inotropes, Line locs for oncology, Sodium chloride, Apomorphine, Aminophylline	Continuous infusions of anticoagulants, Factor viii, Growth hormone, Fertility treatments	

3.2.5.2 Provision of HTHH

3.2.5.2.1 Correlation Between Trust, HA and Commercial Home Care Company Surveys

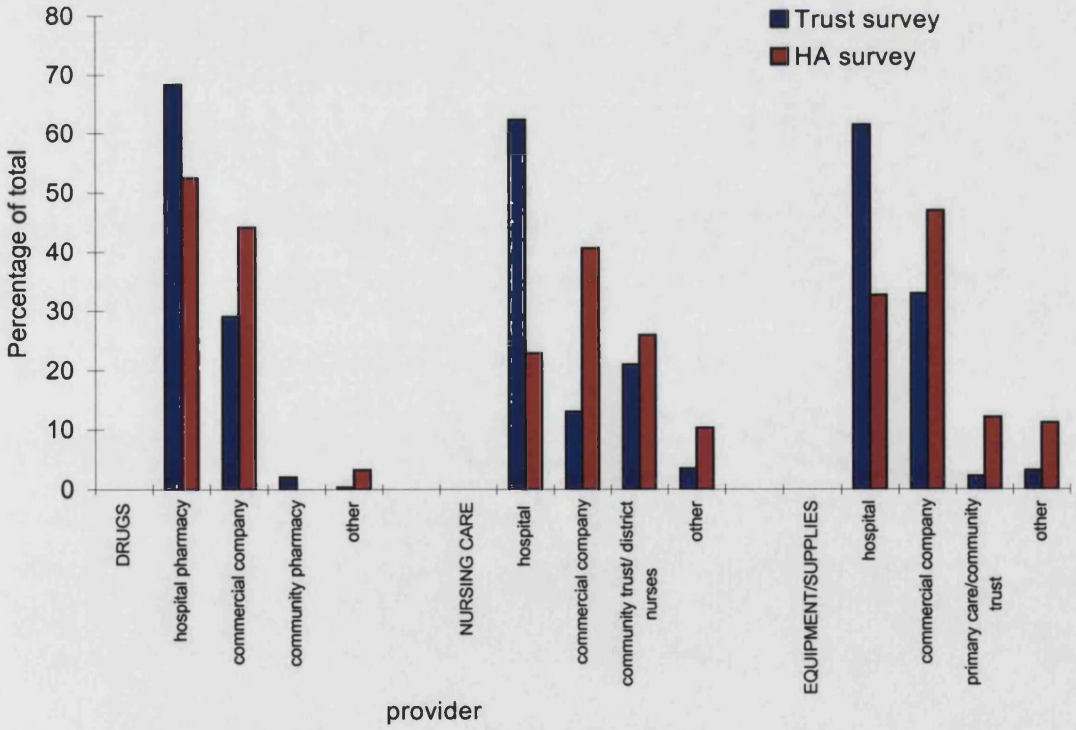
The question where do patients receive their therapy was put into the Trust questionnaire for two reasons. One as a validation to make sure that the respondents were answering questions about home patients and the other to find out what proportion of patients receive infusions at home and which visit the hospital to receive their infusions. This was a difficult question to answer as patients often come into the hospital to have their infusion set up and then go home whilst the drug is infused over a few days or a week. Many people interpreted this to mean where is the infusion set up, which is probably why the numbers for outpatients is higher than might be expected (Figure 3.8). For drugs which are infused once a day or less frequently such as antivirals for HIV and desferrioxamine it can be seen that some patients visit the hospital to have infusions, similar to the US infusion centre model described in Chapter 2.

In by far the majority of cases the patient or their carer administers the therapy themselves (Figure 3.9). When asked who provides various aspects of the care for these patients, it might be expected that the Trust questionnaire would be biased towards Trusts as providers of care.

It can be seen that where HAs contracted for or were aware of their patients receiving HTHH they were more likely to use a commercial provider than the Trusts (Figure 3.26). This raises questions regarding a conflict of interest when HAs pass the responsibility for contracting for HTHH on to the Trusts. If the Trust, has the facilities they are possibly more likely to provide the service themselves than contract with a commercial provider or put the service out to tender as required by European law for any contract worth over 93,896 ECU's (approximately £60,000), total value of contract regardless of time period. There were some comments in the Trust survey about inadequacy of their current provider around lack of ability to respond to changes in therapy at short notice.

It seems that few HAs or Trusts have carried out tendering exercises for purchasing HTHH (see results of commercial company survey, Section 3.2.4.3). This is supported by the findings of the Keele study [42]. The commercial providers are the largest suppliers of nursing care and equipment and supplies according to the HA survey and supply almost as many of the drugs as hospitals but according to the Trust survey all of these services are supplied much more commonly by the hospital than by a commercial provider. The commercial providers claim to have more contracts with Trusts than HAs. Information obtained from the commercial providers shows that 5 of the 6 companies provide nursing care either subcontracting or employing their own nurses. 3 companies have their own aseptic facilities for provision of the drugs, two subcontract this and one company said that the hospital or other organisation provide this part of the "package of care" (Section 3.2.4.3).

Figure 3.26: Providers Of Various Aspects Of Care Comparison of HA and Trust Surveys



In the Trust survey the only item that was more commonly supplied by a commercial provider than a hospital was children's TPN and the equipment and

supplies for both adult and children's TPN. This is in line with the information obtained from commercial providers of HTHH. Many did not provide care under formal contracts but provided HTHH on a patient by patient basis mostly paid for through Trusts and occasionally through HAs. This method of purchasing raises further concerns regarding the monitoring of the quality of care supplied and patient outcomes. It seems unlikely that service specifications would be set up on an individual patient basis and anecdotal evidence suggests that they are not.

These surveys have revealed inequity of quality of care received by patients in different areas of the country. During the telephone survey (Appendix 22) many Trusts revealed that patients are given antibiotics as take home medication and are taught how to draw them up and administer them at home. One Trust (Survey no 182) reported that they currently had 220 cystic fibrosis patients with a bill of £90,000 per month on drugs alone and that they could not be able to cope with the workload of aseptically preparing the doses for their patients. Whereas other cystic fibrosis patients receive a "Rolls Royce" service in comparison with a trained home care nurse, ambulatory pump, aseptically prepared bags and a 24- hour call out service. It has been suggested by a commercial home care provider that after a spate of infections in patients administering their own intravenous antibiotics, the company is only then approached to tender for the service provision. More studies are required to quantify any difference in patient outcomes between patients receiving different level of care but work in the USA has suggested that cheaper care provision in the long run increases the overall cost of treating the patient [279].

From the Trust survey (Figure 3.9) it appears that hospital nurses including outreach nurses accounted for the largest proportion of nurses who administered therapy but for all groups of patients district nurses also featured. Both hospital outreach nurses and district nurses may visit the patient's home to administer each dose. Commercial home care company nurses did not feature highly here. This is probably due to the bias of the Trust questionnaire as providers.

In contrast to the Health Authority questionnaire the Trust questionnaire revealed that most patients receiving home antibiotics for cystic fibrosis, chemotherapy

infusions, antivirals for HIV and desferrioxamine received their equipment and supplies from the hospital but for HPN (for both children and adults) the major providers were the commercial home care companies. This again suggests that HPN is more often contracted for separately by the HAs.

The HAs were not asked who provides a 24 hour helpline for these patients but the response to the Trusts questionnaire shows that in all cases the hospitals most commonly provided this service followed by the commercial home care companies. Primary care provided 24 hour cover in a few cases for all groups except children receiving HPN. The commercial companies all said that they provide a 24 hour helpline. It may be the case that for clinical problems the hospital may provide emergency back up but for mechanical problems or those involving supplies it is the commercial provider.

3.2.5.2.2 Expenditure

3.2.5.2.2.1 Response Rate

The expenditure by HAs on the various home therapies can be seen in Figure 3.5. The HA questionnaire did not provide detailed information on expenditure. It can be seen from Table 3.28 that the HA were more likely to give an idea of their expenditure than the Trusts. This may have been due to the fact that they were asked for less detailed information. It was however often the case that both HAs and Trusts were unaware of their expenditure and the Trusts commonly gave figures for only the drug costs. This suggests that there is little information on the cost effectiveness of home infusions being collected. If costs are not monitored, it seems unlikely that quality of care is being monitored and the HAs and Trusts cannot be monitoring the cost effectiveness of the HTHH that they currently purchase.

Table 3.28, Responses re expenditure on HTHH

	Percent* giving response re expenditure	
	HA survey	Trust survey
Cystic fibrosis	86.0%	51.2%
Chemotherapy	40.0%	38.5%
Antivirals for HIV	50.0%	57.1%
TPN	85.7%	50.0%
Thalassaemia	66.7%	50.0%

Number giving response divided by number giving number of patients>0 multiplied by 100

3.2.5.2.2.2 Health Authority Survey

The results show a wide variation in expenditure on home infusional therapy. HAs were asked to give an approximate annual expenditure in wide bands as it was expected that exact figures might be difficult for a Pharmaceutical or Medical Adviser to obtain. 27 HAs gave no answer at all to the numbers of patients or the expenditure (see Section 3.2.4.1.1). It can be seen that antibiotics for cystic fibrosis were the lower cost higher volume infusions whereas TPN is a lower volume higher cost therapy. The wide range in expenditure on desferrioxamine is probably due to the demographics of the population as thalassaemia is endemic in Mediterranean countries and expenditure is related to the incidence within the immigrant population.

The unpredictability of the annual cost of HTHH to the HA was a problem that was raised in the qualitative data collected (Appendix 19), this was in contrast to the Trust survey where the problem of insufficient funding was raised by 23 Trusts and unpredictability of funding by 5 (Appendix 24).

3.2.5.2.2.3 Trust Survey

Trusts were asked their annual expenditure on each category of home infusion and the number of patients. A very approximate idea of expenditure per patient per annum was calculated by dividing the number of patients by the expenditure (see Table 3.29). One Trust had a cystic fibrosis patient awaiting a heart/lung transplant on continuous home antibiotic therapy. The cost of the drugs alone for

this patient amounted to over £80,000 per year (this patient was excluded from the data shown in Table 3.29). The range of cost for antibiotic infusions for cystic fibrosis and for chemotherapy infusions would be expected to be greater than that for desferrioxamine or TPN as there is a much greater variation in the cost of the drugs given. The cost of an adult TPN patient varied from £10,000-£60,000 per annum. It could be that the lower end of the range was due to a patient (or patients) only receiving TPN for part of the year or having bags two or three times a week instead of requiring them every day. Children's TPN was, on the whole, more expensive than adult TPN probably due to the specific and varying requirement of a child's nutrition compared to that of an adult who may well have standard bags and little variation in nutritional requirements.

It can be seen from Table 3.29 that the cost of treating patients with HTHH varies widely throughout the country. This would in part be due to different patients and patient groups possibly requiring very expensive therapy. However it is very unlikely that this accounts for all of the variation.

There may be some bias in the data on expenditure as it could be that Trusts whose expenditure was large were more likely to know what it was than those whose expenditure was small.

The Monopolies and Mergers Commission report on the proposed merger between Fresenius AG and Caremark Limited [43] shows that over the time period 1992 to 1997 for Caremark and 1994 to 1997 for Fresenius overall real price trends for home infusion therapy dropped. It also shows that Caremark's average price of contracts with HAs is higher than that for Trusts. This is in part explained by large centres who had large numbers of patients and had exercised this buying power in negotiating contracts and whose patients due to the expertise of the centre were less costly for Caremark to service. The costs were excluded from the report to protect the interests of the companies concerned.

Table 3.29- Expenditure By Trusts On HTHH

drug/condition	no of answers	range £s/patient/year	mean £s/patient/year	median £s/patient/year
cystic fibrosis	22	250-25,000*	4,156	2,714
cystic fibrosis excluding drugs only	16	1,000-25,000*	4,707	3,038
chemotherapy	15	160-10,500	3,840	3,333
chemotherapy excluding drugs only	12	1,111-10,500	4,515	3,536
HIV**	8	1,000-31,500	16,250	17,500
HPN adults	15	10,000-60,000	27,461	30,000
HPN adults excluding drugs only	14	10,000-60,000	28,708	30,000
HPN children**	9	15,000-50,000	36,370	37,500
Desferrioxamine	15	500-10,000	5,028	3,650
Desferrioxamine excluding drugs only	13	667-10,000	5,516	5,000

*One patient at £80K/year also excluded. **no figures stated that they were for drugs only rather than entire package of care?

These are broadly in line with the costs that Pilling [6] estimated of treating patients with HTHH in 1995/96. The figures in this report per patient per year were approximately £6,000 for IV antibiotics, £20,000 for antivirals, £3,000 for chemotherapy £35,000 for TPN and £14,000 for desferrioxamine.

3.2.5.2.3 Contracting/Purchasing HTHH Services

It is clear that the responsibility for contracting for the service, providing the service and monitoring the quality of the service provided, lies with different

people in different areas. In many cases the Health Authority assume the Trust or commercial provider is responsible. EL(95)5 [41] clearly placed this responsibility with the Health Authorities.

It was difficult to interpret the answers to the question regarding whether HTHH was purchased as a separate contract or as part of a bulk contract by the Health Authority (Section 3.2.4.1.5). These data show that the majority of HAs contract for these services as a separate contract but over a quarter of respondents have added the money from top-slicing GP budgets in 1995 to their bulk contracts with the Trusts and passed on the responsibility for contracting for packages of care for these patients. This is in line with the findings of Short [42]. Both the HAs (5) and Trusts (2) commented that tertiary centres can cause problems with contracting mechanisms. This can particularly be a problem where a HA sets up a contract with a provider for all of their patients then they have a patient referred to a tertiary centre which may have their own contract with a different provider.

The Trusts were not asked specific questions regarding the commissioning of HTHH but the answers given regarding who supplies the drugs (Figure 3.11), nursing care (Figure 3.12), equipment and supplies (Figure 3.13) and a 24 hour help-line (Figure 3.14) all refer to commercial providers. It may be that the commercial company is entirely responsible for the care of patients at home or the hospital pharmacy and commercial company may be working in partnership to varying degrees. Some have formal partnership arrangements and others work closely with the company as the patients may frequently come in and out of hospital. There has been some conflict of interest in certain places where a hospital pharmacy department have bid for a contract and lost it to a commercial company with whom they then are expected to work, co-ordinating discharge arrangements and in some cases stepping in when the commercial company is unable to supply or respond quickly enough to changes in therapy (Box 2).

Box 2:

> *"Recently home TPN patients have been taken over by commercial companies who have a less flexible approach to formulation changes such that the pharmacy department prepare bags when regimes have to be altered at very short notice".*

22 Trusts said that they did have patients who were receiving HTHH as part of a bulk contract prior to EL(95)5 [41]. In these cases the funding could not have been top-sliced from GP prescribing budgets and therefore it would have been difficult for the HAs to claw back this money from the Trusts to purchase a "package of care" for these patients. This is likely to be one of the reasons that many HAs do not contract separately for HTHH. It can be seen from these data that often *ad hoc* arrangements are in place for the different groups of patients receiving different therapies at home from local Trusts, Box 3.

Box 3

> *"The situation is very complex -diffuse and vague accountability -very fragmented. In short - a mess!"*
>
> *"I have been trying to find out about cystic fibrosis patients as I am sure we have some. Unfortunately I have not found anyone who can answer these questions. This in itself probably indicates lack of any co-ordinated approach".*

Ten Trusts said that patients received home infusional therapy outside the scope of EL(95)5 [41]. One Trust stated that this depended on the interpretation of EL(95)5 [41], as the list of recommended drugs/treatments was not exhaustive and therefore all intravenous infusions administered at home came under EL(95)5 [41]. This again highlights the problems caused by different interpretations of EL(95)5 [41].

The Trusts were asked why their current home care provider was chosen (Figure 3.16). Most said because of the quality of service (37) although only 18 Trusts said that they had an audit system in place to measure the quality of care received

by these patients (see Section 3.2.4.2.13). The next most popular reason was convenience (33) followed by the fact that it was financially attractive (30). Again very few measured value for money or quality of the service the patients were receiving for the financial outlay. 22 Trusts said patient acceptability was a reason for choosing their current provider but only 8 Trusts (Table 3.17) mentioned any kind of patient satisfaction survey when asked about how the service was audited.

Fewer than 20% of the Health Authorities had any future plans for the care of these patients. One Health Authority had decided to give the responsibility for organising care for new patients to the individual clinicians. This does not comply with EL(95)5 [41]. Another was thinking of giving responsibility to the Trusts and had decided to allow diversity or provision dependant on circumstances, two said the provision of the service was going out to tender and one Health Authority commented that an overall approach seems difficult due to the varied patients. None of the HAs gave any sign that they had a long term strategy for either continuing to care for the numbers of patients being treated with hi-tech therapies at home or for coping with and financing increased numbers of these sorts of patients. In the USA, both patients and payers (insurance companies etc) have demanded an increase in the provision of home care services. With increasing problems of antimicrobial resistance, hospital acquired infections and super-bugs in the hospitals in England [280], it is perhaps surprising that the promotion of high quality and cost effective home therapy which has been proven in the USA, and to a lesser extent in the UK (Chapter 2), is not being adopted and planned for *[30]*.

None of the Health Authorities knew of any fundholding GPs who directly purchased HTHH. Pilling and Walley [6] note that there was confusion as to GP fundholder responsibilities for commissioning HTHH and suggested that due to the very small numbers of patients purchasing via consortia of GP fundholders would be more appropriate. The American Society for Parenteral and Enteral Nutrition (ASPEN) have published standards for home nutrition support the most recent update being in 1999 [214] with the aim of assuring sound and efficient home nutrition support care and assist organisations and health professionals in

providing safe and appropriate nutrition care. The standards give examples to ASPEN's multidisciplinary members of implementation of specific standards. It remains to be seen whether primary care groups (PCGs), will be responsible for purchasing HTHH and if so at what level.

Once PCGs attain Trust status they may have to contract for this service. They are being actively encouraged to enter into collaborative commissioning arrangements [281]. Pilling [282] predicts that PCGs and PCTs could become a catalyst for home care becoming the modality of choice in an effort between primary and secondary to care to maximise the efficiency of unified budgets. A Primary Care Trust could decide on a model of provision for all hi-tech therapies from a secondary care outreach service. Alternatively GPs may decide that they wish to care for patients whose only requirement is a course of intravenous antibiotics for example. If an appropriate package of care was available at short notice this might save a hospital admission. It is apparent from these data that GPs do not have any experience in this area. It is beginning to appear more likely from models emerging for the specialist commissioning of other services that some of these high cost, low volume therapies may well be contracted for on a regional basis [283]. It is recognised that the expertise for this does not rest within the PCG/Ts and the very small numbers of patients per PCT would mean commissioning on an individual PCT basis would not be viable unless a change in thinking led to a large increase in numbers of patients.

3.2.5.2.4 Collaboration With Health Authority And Primary Care Colleagues

HTHH is an area of patient care at the primary/secondary care interface. Patients are in their home environment and often geographically closer to the GP than the hospital. Their GP is still expected to look after other ailments that the patient has whilst at home but may not be directly involved with the home infusion, especially since EL(95)5 [41] stopped GPs from prescribing these therapies on FP10 prescriptions. It can be seen from Figure 3.14 that primary care is involved in providing a 24 hour help line for these patients so good communication with all parties having a clear understanding of where their responsibilities lie and who to contact for advice is important. Only 10 (10.6%) Trusts had any shared care arrangements or guidelines for these patients and HAs reported very few

shared care guidelines for home infusions (17.2% knew of a guideline for HPN, 16.1% for home antibiotic infusions and 8.0% for home chemotherapy). Concerns about hand over issues and patient selection were raised in the qualitative data from both the HA (14 comments) and Trust (11 comments) surveys. From these data it would seem that inadequate arrangements exist to ensure that the patient's GP is kept fully informed of the patients' treatment and where his responsibilities for the care of that patient lie.

30 Trusts (31.9%) said that there was some collaboration between the Trust and the Health Authority Prescribing Team. This question was asked as many of the HAs said that the Trusts dealt with HTHH and they were therefore unable to answer the questions. However the responsibility for contracting for HTHH should lie with the HAs (EL(95)5 [41]). This again suggests that the Trusts are providing HTHH which is not covered by EL(95)5 [41] and not contracted for by the HAs. Trusts that did have contact with their Health Authority Pharmaceutical Adviser mainly collaborated over contracts and particular problems which arose or to obtain funding for a new patient. One Trust had regular update meetings and clinical case conferences with the Health Authority, but this was far from the norm, which amounted to occasional telephone contact or meetings in most instances.

3.2.5.2.5 Quality Assurance of HTHH Service

It was apparent from the qualitative data obtained in response to the HA survey that HAs are unclear as to who is responsible for monitoring the quality of care received by patients receiving HTHH [284]. When these data were coded (Appendix 20) it can be seen that there were 12 comments regarding auditing the quality of patient care and 11 comments on how the HAs know whether they are getting value for money. No specific questions were asked in the HA survey regarding the clinical governance of HTHH but the number of HAs who independently raised this as a concern led to specific questions being asked on the subject in both the subsequent questionnaires. It is apparent that there is very little monitoring of quality of HTHH programmes currently in England. When the qualitative data received from the HAs was coded 14 comments showed ignorance/unfamiliarity with HTHH (Appendix 20). These findings are in line

with those of Short [42] who found that the proportion of Health Authorities with monitoring mechanisms in place for their contracts for home chemotherapy, antibiotic and HPN were 76%, 56% and 47% respectively.

The answers that Trusts gave to the questions regarding quality assurance of the home infusion service are perhaps the most worrying of this study. Only 18 of the 94 (19.1%) responders replied "yes" when asked if there was an audit system in place to measure the quality of care received by these patients. Of those 18, 7 did not specify how this was measured when asked, although one of these gave a telephone number of someone who might know, (no answer when called). One said "patient satisfaction" and 7 used questionnaires. The other two answers were "Depends what the individual Trust requires", "May be some feedback from the Health Authority" and "Service assessed periodically". Only 8 out of 94 (8.5%) could specify a method of measuring the quality of care received by patients. This is particularly worrying in light of the fact that the qualitative data revealed 9 comments regarding the inadequacy of their provider's service (Appendix 24). This contrasts strongly with the position in the USA (see Chapter 4).

EL(95)5 [41] was intended to introduce more competition into the home care market so that cost effective care would be provided. The Monopolies and Mergers Commission report [43] on the proposed merger of Fresenius and Caremark, two commercial providers of HTHH, found that the merger would lead to a reduction in competition and would particularly make it harder for the NHS to obtain value for money in purchasing parenteral nutrition for patients at home. If competitive tendering exercises are in place there is pressure for providers to provide HTHH at a competitive cost. If so few Trusts or HAs are monitoring the quality of service that is provided it is inevitable that quality will decrease along with cost.

More Trusts answered the question who specifies audit criteria. In 13 cases it was the Trusts. 4 Trusts said that commercial home care companies specified audit criteria, although when asked the same question no commercial companies claimed to specify audit criteria and 4 said it was the Health Authority. One said

that patients and their carers specify audit criteria to measure the quality of the service they receive. When asked who measures the quality of care received by these patients 11 said that it was the Trust or provider unit, 4 said it was a commercial company, 2 said the Health Authority and 2 the patient/carer. It appears from these data that even when Trusts are specifying audit criteria themselves, and consider themselves to be responsible for audit, they are not carrying it out.

A similar situation existed regarding monitoring patient outcomes. This time even fewer (12) Trusts said there was an audit system in place to measure patient outcomes. 11 said that it was the Trust who specified audit criteria and 12 said it was the Trust/provider unit who monitors patient outcomes.

14 Trusts gave answers to the question "how is this achieved?" (Table 3.17). Some had audit programmes, both small occasional audits and more formal audit programmes, others had systems for long term data collection, or regular audit meetings. One said that the oncology survival rate/cancer cure was monitored. This is a fairly crude audit of the clinical outcomes of patients receiving home chemotherapy infusions. However it is better than the 76 (80.9%) responders who gave no answer. It seems that audit systems need to be put into place in order to ensure that patients being treated with home infusions are doing at least as well as those being treated as inpatient or outpatients. If this were not the case it would be unethical to treat patients with infusions in the domicillary setting. These data suggest that very few Trusts have any idea whether patients being treated at home are faring any better or any worse than they would be if treated in the hospital or if their care was being provided by another provider.

Both HAs and Trusts purported to be providing HTHH because it improves patients' quality of life. There was little evidence for this. They had chosen their current provider because of the quality of care provided but very few were measuring this at all and many of those that claimed they were, were doing it in a very superficial way or "by default". The second commonest reason that Trusts had chosen their current provider was convenience, convenient for whom, the patient or the purchasers and providers of HTHH? 30 Trusts had chosen their

current provider because they were financially attractive but they then failed to measure the quality of care received by the patient or patient outcomes. As was shown by Birnbaum *et al* [279] those providers that appear cheaper can end up being more expensive in the long term due to poor patient outcomes and higher incidence of complications. 14 Trusts said there was "no available alternative" which perhaps highlights the lack of competition in the current home infusion market referred to by the Monopolies and Mergers commission in their report [43].

Four out of six commercial providers knew of any HAs or Trusts with whom they had contracts having an audit system in place to monitor the service they provided or to measure the service provided against agreed service specifications. Only one company knew of any HA or Trust with systems in place to measure patient outcomes or benchmark the service provided against that of other providers. One company stated that they had initiated all of the audit systems in place with HAs and Trusts as they wished to differentiate themselves from their competitors on quality grounds.

3.2.5.2.6 Role of the Pharmacist

The areas where pharmacists presently have the greatest input into HTHH are pharmaceutical advice to the prescriber, supply of drugs, aseptic reconstitution and provision of formulation and stability information which is what might be expected, as they are traditional roles of the pharmacist.

3.2.5.2.6.1 Contracting

Although 63 of the 94 responders said that pharmacists were involved with setting up the HTHH programme and 59 said they were involved with setting service specifications very few were involved with market analysis (33) or contracting for the services (42.5) that many of them were themselves providing (Figure 3.15). It would have been interesting to ask how many Trusts had any service specifications for the provision of HTHH. The reason that pharmacists were not involved with setting them could be that none had been set. 8 Trusts listed other people who were responsible for setting service specifications, these

included the HA, consultants, pharmacy managers, directorate managers, nurse managers and the business manager for nutrition.

3.2.5.2.6.2 Co-ordination and Communication

Pharmacists in the USA have had a major role in the co-ordination of the home care programme (Section 3.1.6). It appears from these data that the pharmacists main role in HTHH was communication with other health care professionals (83) and with patients and their carers (76). Only 60 said that they were involved with communication with other pharmacists which is surprising in a hospital pharmacy environment where there may well be a specialist pharmacist looking after nutrition, paediatrics or HIV for example and another pharmacist involved with aseptic dispensing. Patient selection was left up to medics in nearly all cases where the person responsible was specified. Only 35 Trusts said that pharmacists had any involvement in patient selection. This is in contrast to the situation in the USA where pharmacists have become heavily involved in patient selection, education and support (Section 3.1.6).

3.2.5.2.6.3 Education

An area where pharmacists often have a major role in the hospital environment generally is in education. Relatively low numbers of pharmacists were involved with education regarding HTHH, an area where a great deal of education of both patients and staff is necessary for safe and effective therapy. Only 5 Trusts said that pharmacists were "very involved" with competency assessment of the patient or their carer and 15 had "some involvement". This was a task mainly left to the nursing staff or in a few instances to a commercial provider. The largest role that pharmacists had in education was that of educating other health care professionals (61). 43 Trusts said pharmacists were involved with the design of written information regarding HTHH and 42 were involved with training patients and their carers how to administer their medication at home.

3.2.5.2.6.4 Supply

72 of the Trusts were involved with the supply of drugs and aseptic reconstitution and filling of infusion devices. If the Trust did not supply the drugs a commercial home care company most commonly supplied them.

Pharmacists in the USA have reported a strong involvement in selection of infusion device. This does not appear to be the case in England. 23 Trusts said that pharmacists were "very involved" with selection of infusion pump and 32 had "some involvement". Again where commercial companies were providing HTHH they were responsible for selection of infusion device and maintenance of pumps. Medical electronics and supplies departments of hospitals and specialist nurses were the other people responsible for maintenance of the pumps; there was little pharmacy involvement (19).

3.2.5.2.6.5 Quality Assurance

Quality assurance is another area where pharmacists have experience. The numbers involved with quality assurance of the provision of hi-tech health care to patients at home was disappointingly low.

24 Trusts were involved with quality assurance of the infusion pumps and only one Trust with no involvement gave an answer for who was responsible. This suggests that either no one is responsible or no one knows who is responsible. Pharmacists should be happy about the accuracy of delivery of infusion devices that they are filling for patients' use at home. These data would suggest many have no idea who is taking responsibility for quality assurance of the pumps.

60 said that they were involved with compliance with regulations such as Good Manufacturing Practice. As 72 were supplying and aseptically reconstituting drugs or filling of infusion devices it would be expected that this number should be the same. Only 8 Trusts were "very involved" with quality assurance of the home infusion program and 33 had some involvement. Even fewer (40) had any involvement with ensuring that service specifications were complied with. Comments included "I do not know of anyone performing" and "no service

specifications that I know of". In the main there were not answers to the question who was responsible if the pharmacist was not. It seems that in many cases it is only the statutory monitoring of quality that is being carried out. It appears that it is easy to become caught up in the vital quality assurance of the product manufactured in pharmacy but very few organisations are taking a step backwards to look at the bigger picture and the quality of the whole package of care received by these patients and how this may affect patient outcomes.

3.2.5.2.6.6 Clinical

There was more pharmacy involvement with clinical matters. Pharmacists did have a role in giving pharmaceutical advice to the prescriber (86), providing formulation and stability data (83) and maintaining prescription records (78). These tasks were performed by Trusts even when a commercial company was supplying medication to the patients in their homes. 71 were also involved with choice of appropriate drug therapy and 43 were involved with documentation of a pharmaceutical care plan for the patients. More pharmacists had "no involvement" in selection of venous access device (73), documentation of a pharmaceutical care plan (47), interpreting laboratory tests (40), providing a 24-hour help line (60) and monitoring patient adherence (56) than had any involvement. Selection of venous access device was the domain of the medical and nursing staff although one Trust said that this was protocol driven.

3.2.5.2.6.7 Other Roles of the Pharmacist in HTHH

Other roles of the pharmacist in the provision of HTHH included general queries and advice regarding interactions, advice regarding terminal care and supply of diamorphine syringes, identification of other therapies that could be practically dealt with on a home care basis, negotiation with purchasers re EL(95)5 [41] budget, ordering of blood test etc, ordering and monitoring expenditure and billing other HAs via contract or Extra Contractual Referral and costing.

It is apparent that there are potential roles for the pharmacist in this area but in many places these have not been fully developed. Many pharmacists have the

skills to train and educate patients and their carers and other health care staff, particularly in areas where they have more knowledge and experience than any other health care staff such as in handling cytotoxic medication and waste. They have developed skills in quality assurance of other services they provide both in quality assurance of products supplied and in validating processes used in manufacturing techniques. In order to hold a Medicines Control Agency "specials licence", which many of these Trusts do, a high level of competency in quality assuring both product and process is required. Colleagues in the US have proved, more than a decade ago (2.3.7) that pharmacists can effectively co-ordinate a home care service. They have an important role in patient selection, continuous quality improvement and quality assurance of the service and are often responsible for selection of infusion device and venous access device and therapeutic drug monitoring, in addition to the traditional roles of providing formulation and stability data and giving pharmaceutical advice to the prescriber, and supplying drugs in a ready to use form.

The shortage of hospital pharmacists in hospitals in England in recent years may be a contributory factor in the lack of pharmacist involvement in HTHH programmes [285].

Pharmacists in England have not realised the full potential of their role in the provision of HTHH and in many cases are the best placed healthcare professional to take on these new roles [286].

3.2.5.2.6.8 Level of Awareness of HTHH Amongst Staff Groups

The level of awareness of various staff groups of HTHH as perceived by the hospital pharmacists, who responded to the Trust survey, is shown in Figure 3.19. In all cases, except pharmacists, the highest peak is for a low level of awareness. The highest peak for pharmacists is for a moderate level of awareness. Doctors had the smallest numbers for a high level of awareness and most "don't know" responses were for hospital managers. This could have been that it was the pharmacists responsible for aseptic manufacturing who were asked to complete the questionnaire and it might be that their pharmacy managers are

more likely to be in touch with Trust managers. Some pharmacists commented that the staff involved with the care of these patients have a high level of awareness but others are completely unaware of the potential for treating patients with home infusions. It would be interesting to know whether there are different schemes going on within the same Trust for different groups of patients to provide HTHH which have no contact with each other. It seems probable that this is the case (*Box 4).*

Box 4

Pharmacy need to become involved in a Trust wide policy on home infusional therapy, rather than different areas doing their own thing and everyone pulling in different directions.

The situation is very complex -diffuse and vague accountability -very fragmented. In short - a mess!

I'm sorry it's such a mess! I've collected information from three different specialties; paediatrics, chemotherapy/production, HIV all involved in hi-tech therapy.

3.2.5.2.7 Limitations Of This Study

Limitations have been discussed throughout this chapter. This information goes some way towards establishing the current situation with regard to HTHH and has highlighted the complexity of contracting mechanisms. Accurate information on the numbers of patients being treated with HTHH cannot be obtained, as there are so many contracting mechanisms in place and the number is also not static. This data would need be interpreted in conjunction with accurate demographic data of the incidence of need in the population at the time of the study to draw firm conclusions about geographical differences in the provision of HTHH. It is unlikely that all the geographical variation can be explained by demographics.

Some patients will be counted twice in the returns from Trusts, HAs and commercial providers. Theoretically if the HAs were aware of all of the HTHH

they were purchasing then the returns from the Trusts and commercial home care providers should add up to the numbers of patients the HAs were commissioning care for. It can been seen from these data that this is far from the case.

All of the surveys reported required the respondents to spend time collecting the information. It may have been that the questionnaires were not always targeted at the most appropriate member of an organisation. It was also difficult to ask people for the same information twice to triangulate the data but some effort was made to do this with the Trust survey and the HA data was compared with that of Short [42] and the Monopolies and Mergers Commission Report [43].

Limited information was available, as the questionnaires needed to be short enough to ensure a good and therefore representative response rate.

3.2.6 Conclusion

These data have highlighted both the benefits of HTHH and some of the problems with the way it is purchased and provided in England under EL(95)5 [41]. The complexity of contracting mechanisms has led to a service which is often fragmented. Different specialities are not working together to provide a high quality home infusion service for their patients.

This work supports the conclusions of Short [42] that EL(95)5 [41] has led to inequity in the provision of home infusions with some being contracted for by and paid for by the HAs and other patients relying on whatever service their local Trust can provide. It seems nonsensical that the way HTHH is funded and provided depends upon what prescribing of HTHH GPs were willing to take on prior to 1995. Most HAs have not invited tenders for provision of HTHH and commercial companies report that most of their work is from contracts with Trusts on a patient by patient basis. There are geographical differences in contracting mechanisms, in who is providing "packages of care" for these patients and on the numbers of patients being treated and indications for home infusions. There is also an apparent variation in cost and a lack of information as to how much is being spent on treating patients with home infusions.

In light of the recent emphasis on clinical governance in the new NHS, the most worrying findings of this study were the lack of monitoring of contracts and lack of requirement for quality assurance of service provision/ outcomes monitoring or benchmarking. Pilling [6] recommended in 1995 that consultants and purchasers agree the most appropriate clinical outcomes data that should be provided to purchasers to enable them to purchase more effectively, but this is very rarely seen. This is in stark contrast to the situation in the USA where there are strict accreditation standards and benchmarking is a requirement laid down by purchasers. HAs have a poor understanding of a service for which EL(95)5 [41] gave them responsibility. There is very little evidence as to whether the care received is cost effective and whether patients are fairing better or worse than they would be as inpatients. There is confusion as to whose responsibility monitoring the quality of care and patient outcomes is. Providers of HTHH have very little information to compare their service against that of others. What is an acceptable line infection rate, readmission rate etc?

This highlights the urgent necessity to build quality monitoring into contracts and to collect information on clinical outcomes of HTHH which can be used to define acceptable standards and improve patient care. This has been addressed in the United States but never in the United Kingdom where the systems for the provision of health care are very different. The commercial, political and patient forces are very different in the UK due to the differences in the way health care is funded. This means that different mechanisms have had to drive the quality agenda. The government has recently tried to address this by introducing clinical governance and to enforce it by setting up the Commission for Health Improvement [62]. These mechanisms seek to improve quality and learn from current best practice in all areas of health care within the NHS but these mechanisms do not appear to be providing an early focus or catalyst for change in the UK home infusion market.

This work has identified the need for sharing of information on outcomes of home infusion therapy and the processes leading to those outcomes. It is important, if providers are to compare information to identify their strengths and

weakness, that like is compared with like. In the United States an industry has developed around this but the tools used there do not easily fit with the health care systems of the United Kingdom. It was therefore decided that to facilitate the benchmarking of home infusion providers in the UK a benchmarking tool should be developed.

4 Benchmarking

4.1 Literature Review

4.1.1 The Quality Concept

The Japanese were the first to embrace the concept of quality as a philosophy for managing business organisations taught by quality management gurus such as Deming and Juran during the 1950s [287]. Deming, taught statistical techniques of quality control. He argued that improved quality leads to decreased costs, increased profit and to the company staying in business. Juran also looked at the contribution of quality to reducing costs and introduced the "fitness for use concept" defining quality as product performance that leads to customer satisfaction. Crosby [287] introduced the "zero defect" concept. He believed in changing the culture and attitudes of an organisation to focus on prevention and producing everything "right first time". He estimated that service companies spend about 40% of their operating costs on doing things wrong.

Techniques such as Statistical Quality Control, Continuous Improvement, Total Quality Management (TQM), Quality Function Deployment, Zero-Defect and more recently Business Process Reengineering (BPR) have over the past few decades had a huge impact on the management of organisations. There have been literally thousands of books written on these subjects and it is outside the scope of this research to study these management techniques.

TQM is about the continual improvement of quality through an organisation. Striving through the workforce to find new ways of improving quality. TQM also encompasses the optimisation of both internal and external operations and this is where the tool of benchmarking is commonly employed. BPR involves radically rethinking the way things are done. Its advocates claim that it can lead to huge leaps in performance through major organisational change [288]. It focuses more on thinking outside of the box, "don't automate obliterate", "don't cement the cow paths", Tom Peters [289].

The Deming Prize, the American Malcolm Balbridge Award and the European Quality Award were all established to promote the importance of quality. They all require self-assessment by an organisation and demonstration of the successful use of benchmarking as a quality improvement tool.

BS 5750 was one of the first recognised quality standards in Britain developed from standards for defence procurement. It had shortcomings amongst which was that for world class competitiveness there had to be a common international standard. Pressure from the motor industry led to the formation of the International Standards Organisation (ISO) during the early eighties. The ISO 9000 series standard was developed in 1987 by the ISO Technical Committee 176. It encourages documentation of processes but has been criticised by companies such as Motorola (1988 winner of the Malcolm Baldridge Award) and Sun Microsytems for having no direct connection to quality of a service [288]. ISO 9000 is currently being updated to give a more rigorous standard based on the systems used by Ford, General Motors and Nissan.

4.1.2 History of Benchmarking

Benchmarking is recognised as a useful, if not new, tool used in quality initiatives such as TQM, BPR and process redesign [290, 291]. It aims to achieve leaps in performance and quality in an organisation by comparing current practices and processes with outstanding performance of others performing a comparable process (or ideally the "best of the best") and through an understanding of the processes which lead to this superior performance adapting and developing current in-house processes.

Figure 4.1 shows the place of benchmarking as a tool in operations management.

Figure 4.1, Where does benchmarking fit in as a tool for operations management?

(From a Benchmarking in Public Services Workshop, Bone and Robertson, London 3rd November 1998).

audit and expectation		*evidence base*
Business Excellence Model European TQM		Value Management Best Value Framework
Quality Assurance ISO 9000	BPR **Benchmarking**	Value analysis - existing Value engineering - new design
Statistical Process Control Quality Control BS 5701	last century Work Study and Work Measurement	Function Analysis System Technique
doing the thing right	*hybrid/derivatives*	*doing the right thing*

The Xerox Corporation is credited with being the first in the Western world, in 1979, to fully embrace the concept of benchmarking and use it to turn around their business. They found that their Japanese competitors were able to sell products for less than the price it was costing Xerox to manufacture, even though the quality of the Japanese products was twice as good as those manufactured in the United States. They decided to encompass quality improvement initiatives and change their processes by learning from the 'best of the best'. They learnt from their competitors in Japan, within the same industry, but also from others working in other industries with the same problems, such as that of distribution

where they formed a benchmarking partnership with L.L. Bean, a mail order company. Their success in winning the prestigious Malcolm Baldridge National Quality Award in 1991 inspired others to adopt the concept of benchmarking. The benchmarking experiences of Xerox were published by Robert C. Camp in 1989 [292].

Benchmarking was being used in various forms long before the Xerox Corporation's success. Codling [293] noted that there are records dating back to ancient Egyptian times pointing to the use of benchmarks in construction work. Loh [288] cites both Frederick Taylor's work in the late 1800s on the application of a scientific method of business encouraging comparison of work processes and the common practice during the second world war of companies to "check" with other companies to determine standards for pay, work loads, safety and other factors as examples of benchmarking, in place well before the 1970s. Hamington [294] says benchmarking is one of the oldest improvement tools in the world stating how even the Bible's Old Testament has many examples of how progress was made by studying what others were doing.

The Japanese were the first to realise the importance to business success of taking on the quality concepts taught by Deming and Juran [287]. The Japanese practice of *shukko* has been around for many years, it involves loaning employees to other organisations so that they come back with new and innovative ideas on changing processes within their own organisation. The word *dantotsu* means striving to be "best of the best" and is used in *kaizen* (continuous improvement).

Watson [295] outlined the historical development of benchmarking in manufacturing industry starting with the practice of reverse engineering, moving on to the Xerox model of competitive benchmarking of the late 70s, then process benchmarking, strategic benchmarking and finally global benchmarking.

4.1.3 What is benchmarking?

4.1.3.1 Definitions

There are many definitions of benchmarking with various differences in emphasis depending upon what an industry is hoping to achieve from the benchmarking process. They all involve understanding current processes and adapting them for the better based upon learning from others.

The Xerox Corporation defines benchmarking as:

"A continuous, systematic process of evaluating companies recognised as industry leaders, to determine business and work processes that represent 'best practices' and establish rational performance goals." [294].

Watson [295] gives two definitions. The first is that of The Westinghouse Productivity and Quality Centre:

"Benchmarking is a continuous search for and application of significantly better practices that lead to superior competitive performance."

and the second developed at the APQC by the International Benchmarking Clearing House Design Steering Committee which represents a consensus among more than 100 companies:

"Benchmarking is a systematic and continuous measurement process; a process of continuously measuring and comparing an organisation's business processes against business process leaders anywhere in the world to gain information which will help the organisation take action to improve it's performance.".

The British Institute of Management in its publication Understanding Benchmarking, defines benchmarking as:

"The process of identifying, understanding and adapting outstanding practices and processes from organisations anywhere in the world in order to help your own organisation to improve it's performance.".

This last definition uses the word "outstanding" rather than "best", as what is best for an organisation depends upon its unique situation. The word "adapt" is used rather than "adopt" as benchmarking is not about observing outstanding processes and copying them, for an outstanding practice to work in another organisation it must be changed to make it effective. As Deming advised "adapt don't adopt" [296].

When the Milliken Company won the Malcolm Baldridge Award Roger Milliken described benchmarking as "stealing shamelessly". Motorola even used the code name 'Bandit' to identify its pocket pager project which was built by incorporating the best practices of many companies [288]. Unlike its predecessor, competitive analysis which incorporates such activities as reverse engineering where a company takes a competitors products, tests them and strips them down to find out how they have been manufactured, benchmarking is a fundamentally open process of sharing honestly rather than industrial espionage.

Various benchmarking organisations have developed their own version of a code of conduct for benchmarking studies; many organisations use The Benchmarking Code of Conduct of the International Benchmarking Clearing House [295, 297, 298]. This aims to ensure openness and honesty during the benchmarking process and ensures that confidential information is used only for the purpose of a benchmarking study. These concerns over sharing of information highlight another advantage of not working with direct competitors; information can be freely shared without the risk of losing competitive advantage in the field.

Other definitions of benchmarking are more financially orientated such as that of Gondringer of the Association of Nurse Anaesthetists in the USA

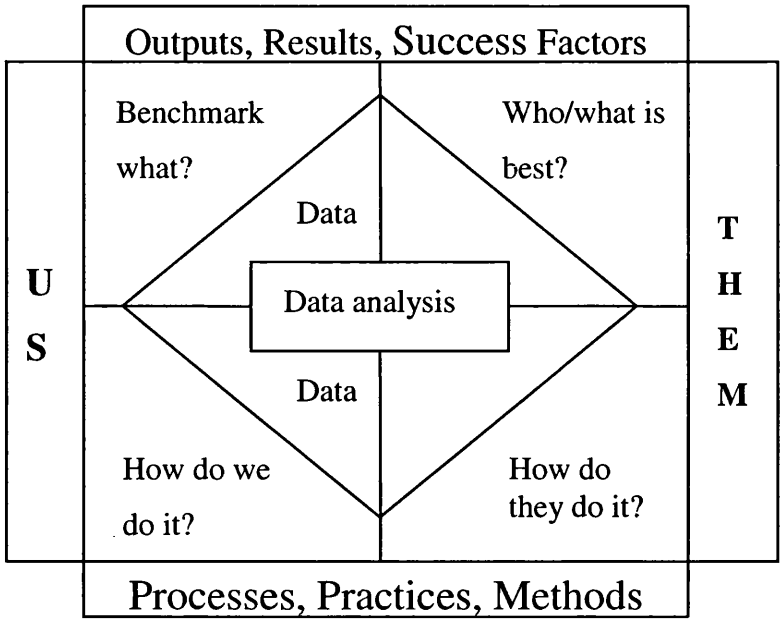
"Benchmarking is an approach of reducing costs while improving productivity. It is a process of organisations learning or measuring their organisation against

the leaders in the industry to improve performance outcomes in a defined service area while keeping costs to a minimum." [299].

Tucker *et al* [300] noted that managers at Xerox tended at first to concentrate on comparative costs but as they became more knowledgeable about benchmarking they discovered that understanding practices, processes and methods is more important because these define the changes necessary to reach the benchmark costs. It can be seen from the above definition of benchmarking used in a health care environment that benchmarking in health care has not yet evolved as far as it has in manufacturing industry.

It is important that the difference between benchmarks and the process of benchmarking be distinguished. People often assume they are benchmarking when all they are doing is comparing benchmarks. This has tended to be the case with hospital league tables in the United Kingdom. The benchmarks are not homogenous and there is no examination of practices or processes or learning from the experiences of others. MacDonald [296] defines the term benchmark as a reference or measurement standard for comparison. It is important that benchmarks, performance indicators or outcome measures used in a benchmarking process are comparable and representative of better or best practice [44, 301]. Bullivant [290, 302] stresses that data is only part of the information you need for successful benchmarking. Watson in his Benchmarking Template (Figure 4.2) illustrates this. Equally important is the knowledge of how your own organisation works and the learning from others who are better. As Harrington puts it "don't set benchmarks, do benchmarking" [294].

Figure 4.2, Benchmarking Template



4.1.3.2 Types of Benchmarking

Three types of benchmarking are generally recognised, internal, competitive and functional, although definitions vary. Codling describes three types of benchmarking, internal, external and best practice [293], whilst Camp defines internal, competitive, functional and generic process benchmarking [292].

Internal benchmarking is heralded by many authors of benchmarking textbooks as a good place to start benchmarking initiatives. It is often easier and cheaper to benchmark internally within an organisation (either at the same or another location) but it is unlikely that improvements will be as great as those achieved when benchmarking with external partners who think outside of organisational boundaries. The level of excellence achieved will be limited to that of the best performer within the organisation. Internal benchmarking has the advantage that data is often more easily available and directly comparable and is relatively easy and quick to implement the process adaptations.

External benchmarking may be against competitors or partners from a completely different company or even industry. Camp [292] subdivides this into competitive and functional benchmarking. Competitive benchmarking has disadvantages of the fact that the companies are directly competitive and there are legal and ethical considerations which can make the open sharing of information difficult. There is also the worry of whether a competitor can be trusted not to impart misleading information.

Functional best practice benchmarking involves benchmarking against an organisation who have comparable processes but are not a competitor such as the L.L. Bean/Rank Xerox success, where Xerox learned from L.L. Bean's packing process which was similar to their own but three times faster [300]. This type of benchmarking has the advantage that you can potentially become better than your best competitor by using ideas from outside of the industry.

One widely quoted case of how it is possible to learn from an external benchmarking partner outside of the industry is that of Bath Iron Works who carried out a benchmarking exercise with Disney World in Florida. They were able to learn from Disney's world class maintenance routines for their air pneumatics systems within their animated characters [296]. This type of external benchmarking is more likely to lead to major innovation as Theodore Levitt found in his famous paper "Marketing Myopia" published in the Harvard Business Review in 1960.

Best practice benchmarking involves finding the undisputed leader in a process that is critical to business success, regardless of sector or location. This means the best for the organisation studied, for the process being examined, and this will not be the same for any two organisations looking for benchmarking partners. The only way to find the best for an organisation is to systematically plan and collect data on which company is the 'best' to benchmark against.

Generic benchmarking involves looking at a key business process which may be common to many industries such as pay roll generation. Benchmarking is

conducted across various industries. These types of benchmarking activities are those that typically show breakthrough results [303]. An example of this was when a team at DuPont wanted to improve the manufacture of ammunition shells making them smoother and shinier and chose a cosmetics manufacturer who consistently delivered smooth shiny and by co-incidence ammunition shell shaped lipstick cases as a benchmarking partner [296].

4.1.4 Benchmarking As A Tool In Service Industries

The concept of looking at process and best practice and learning from others has been shown to be as applicable to service industries including health as to manufacturing industry [294, 303, 304] [305]. There are numerous examples of how benchmarking has led to breakthrough improvements.

TNT won both the 1994 UK Quality Award and the European Quality Award in 1995. TNT use internal benchmarking in the form of Performance League Tables linked to various incentive programmes. They competitively benchmark themselves against their major competitors such as Parcelforce, Red Star and Interlink and used functional benchmarking against others providing similar services such as benchmarking their warehousing and distribution system against that of Cow and Gate [293, 294]. The benchmarking experiences of Post Office Counters, Royal Mail, the Australian National Roads and Motorists Association (NRMA), Leeds Permanent Building Society, Nationwide Building Society, Bradford Community Health NHS Trust, Leicester Royal Infirmary NHS Trust and benchmarking studies in the NHS from the Audit Commission are used as case studies by Zairi [294]. Codling describes how British Rail's Network South East sought out "best practice" when trying to improve the cleanliness of their trains. At British Airways it took 11 people nine minutes to clean a 250-seat jumbo jet. British rail learned from British Airways cleaning process with the result that it now takes just eight minutes to clean a 12-coach 660-seat train [293]. General Motors used a service industry American Express as a benchmarking partner to gain new ideas on customer satisfaction rather than comparing themselves to another company in the manufacturing sector.

4.1.4.1 Benchmarking in Healthcare

Initially the providers of healthcare throughout the world viewed TQM and other quality improvement principles as business management practices that were not applicable to their field but during the 1980s the quest for improved outcomes with limited resources made the healthcare industry look elsewhere for answers [306-308]. Other service industries had begun to adapt the manufacturing quality techniques for use in their industries and it was realised that adaptation to healthcare was not only possible but extremely useful, benchmarking being both process driven and customer orientated. Quality initiatives such as TQM and BPR have since been applied with varying degrees of success to health services [306, 307, 309]. The term Continuous Quality Improvement (CQI) has been adopted by many who have adapted TQM to the health care industry [134, 291, 310].

The need to measure and monitor the quality of medical care has been extensively discussed. Hopkins [311] and Bullivant [290] both quote the World Health Organisation's target 31 of it's "appropriate health care and technology programme" that by 1990 all Member States should have built in effective mechanisms for ensuring the quality of patient care. A theme that was taken up in the UK in 1989 in the Government White Paper "Working for Patients" [312] which required that each health district have medical audit in place by 1991. "Caring for People" in 1990 and almost every other White Paper from the Government since has placed emphasis on quality issues the most recent being the emphasis on Clinical Governance in the 1997 White Paper "The New NHS: Modern and Dependable", reiterated in the National Plan of July 2000 [5]. Joss *et al* [307] discuss the difficulties of applying TQM to the NHS, one of the major concerns being the definition of quality given the different perceptions and requirements of different groups of staff and the wide range of stakeholders in the NHS. Øvretveit [308] points out that whereas in most industries a quality service is one that provides customers satisfaction i.e. provides them with what they want, health services must provide people with what they need as well as what they want and do so at the lowest cost . Williams [305] noted in 1996 that in the NHS, benchmarking has started to become widespread, with both formal and informal benchmarking clubs and centrally driven initiatives. Outcomes in

health are often not as simple to define or to measure as they might be in other industries. This coupled with the way the NHS is funded in Britain leads to further challenges in the adaptation of benchmarking to health provision.

Donabedian is an acknowledged guru of medical audit and quality assurance. He suggested in 1966 that the quality of care of patients could be audited in three dimensions - structure, process and outcome [311]. Structure involving the buildings, equipment and availability of appropriately trained staff, process referring to the activities of medical care and outcome referring to the change in the patient's current or future health that can be attributed to a medical intervention. Many home infusion outcome measures have been built upon this principle [45, 46, 313] (described later in section 4.1.4.1.1.).

Benchmarking has been reported to be a useful and successful tool in CQI in health care in the USA [303]. The SunHealth Alliance (Charlotte, NC), has been active in promoting and facilitating benchmarking of health services [314, 315]. Bergman reports reducing average length of stay for pneumonia patients from 8.1 to 6.7 days after comparing its processes with three other hospitals [314]. Mohr *et al* [304] describe how benchmarking can play an integral role in clinical improvement work and can stimulate wise clinical changes and promote measured improvements in quality and value. Lagoe *et al* [316] also report a reduction in length of stay after benchmarking their East coast hospital with similar hospitals on the West cost of the US. A 28% reduction in mean length of stay for total hip replacement and 17% reduction in mean length of stay for stroke and acute myocardial infarction were reported. Barnes et al [317] used benchmarking to streamline their processes for caring for coronary artery by-pass graft patients. They achieved reduction in costs and average length of stay whilst maintaining a stable mortality rate. Gift *et al* [291, 318] suggest that a collaborative approach to benchmarking in health care is successful having the advantages that it is economical, permits more organisations to take advantage of it's potential and promotes much needed co-operation between health care organisations.

Successful benchmarking projects have been reported in health care in the NHS [287, 290, 294, 298, 302, 319-321]. Lam [287] points out that clinical practice has remained a challenge for measurement and comparison and has not often been the subject of benchmarking but has tended to remain within the domain of clinical audit.

During early 1990's in the UK, medical audit and clinical audit (which incorporates care given by other professionals as well as surgeons and physicians), became popular tools used to promote continuous improvement in the quality of patient care either directly or indirectly. It was recognised by many health care workers that objective measurement of baseline data before the implementation of a quality improvement programme allowed evidence for the benefit of that programme to be assessed.

The idea of using benchmarking in the NHS arose from discussions with the Patient's Charter Implementation Group to fulfil the need for a systematic approach to assessing practice. It was recognised that all sites visited had mixed elements of very good practice and areas in need of improvement. A Benchmarking Club was launched in January 1993 sponsored by the NHS Executive. Ellis [319] points out that much of the benchmarking in the NHS has focused on organisational benchmarks such as targets set for the Patient's Charter and are not specific to clinical practice.

In the UK there has been a tendency for outcomes to be service related rather than clinical. An example of this is the hospital league tables published by the government which were heavily criticised for not taking into account clinical outcomes. Length of hospital stay could be very short in one hospital but twice as many of their patients may be readmitted within a week than those of a hospital with a longer length of stay.

Lam [287] discusses the potential advantages of benchmarking over clinical audit. She argues that benchmarking is an ideal instrument for enhancing peer group learning in a non-threatening and flexible way. It allows dissemination of good practice with the understanding that no-one is best at everything and

encourages open and shared learning in a structured way. Benchmarking can be used as a tool to facilitate structured comparison of process, practice and performance between units within an organisation or with other organisations, as long as units have a clear understanding of processes, clear criteria and respect privacy of their benchmarking partners. She points out that clinical audit tends to be conducted internally and is centred around learning how to improve next time whereas benchmarking is concerned with mapping best known practices wherever they occur and sharing learning in an open and structured way.

Bullivant [290] gives the following explanation of the relevance of benchmarking to health care " In the hospital it is about getting the patient to the best treatment as quickly as possible, providing that treatment on the basis of knowing what works, and then getting the patient home or on to appropriate care as quickly as possible, consistent with their needs. It is about staff in the hospital and outside working together to achieve that care for patients, so for example it is about getting the patient, surgeon, anaesthetist, nurses and medical records to the theatre at the same time and it is about 'creating' the department for getting people home rather than ward nurse, medical records, pharmacy and ambulance service all thinking it's not their fault if you stay in hospital another few hours or another night after being discharged by the consultant".

One of the most important considerations when carrying out a benchmarking exercise is ensuring that like is compared with like. If the benchmarks are not comparable then they will not help to identify best practice and therefore point to process improvement. This is a problem in health care. There has been a great interest in recent years in outcomes monitoring. The development of meaningful performance indicators, clinical and non-clinical outcomes and benchmarks is a difficult task and is in itself a fast growing discipline. It is easy to criticise indicators developed for the purpose of comparison but there is an argument that measuring something is better than nothing and certainly they act as a starting point for asking why there are differences between different organisations and why trends are occurring within an organisation. Used in isolation they are often meaningless but if used as a starting point they can help identify a problem or in the point to an area where practice can be improved. Eaton [322] warns that the

use of benchmarking in the NHS will be widely adopted as laid out in the White Paper, The New NHS [4] and a recent Health Economics Report, Benchmarking and Incentives in the NHS. Benchmarking is widely used to monitor performance in social services and the Commission for Health Improvement and the Audit Commission will soon start to inspect against benchmarks of acceptable service level and cost. Eaton [322] notes that there is a lack of appreciation of the cost of implementing a performance management culture in the NHS.

4.1.4.1.1 Benchmarking and Outcomes Monitoring of Home Infusion Services

The first standards for accreditation of home care were published by the JCAHO in 1988 [323] and included standards on specific areas of concern such as patient rights and responsibilities, patient care, safety management and infection control, home care record, quality assurance and management and administration [323]. It was soon recognised that accreditation of a home health care agency did not necessarily signify quality and in response to this the JCAHO Home Infusion Therapy Task force developed a set of clinical indicators that focused on outcome designed to lead to assessment and improvement of process.

Six indicators underwent alpha-testing in 1992. These were

- Unscheduled inpatient admission by type of therapy
- Discontinued infusion therapy by type of therapy
- Interruption of infusion by type of therapy
- Prevention and surveillance of infection by type of therapy
- Adverse drug reaction and
- Patient Monitoring and appropriate intervention [313].

Beta-testing of these same indicators was discontinued due to reasons unrelated to the quality or value of the indicators themselves. There was a need for broader performance measures and simpler methods of data collection and analysis. Other organisations both commercial and non-commercial developed new performance measures with broader application to the entire home care market [271].

In 1989, Barget and Zink [324] identified a need for the development of a method for evaluating the quality of care of patients receiving complicated home care procedures. They developed a clinical indicator tool based on absence from complications of intravenous therapy, patients'/carers' knowledge of intravenous therapy and patients'/carers' being able to demonstrate ability to manage their IV therapy. The tool served as a useful first step, it had weaknesses identified during piloting, one of which led to the addition to the tool of a measure of complications due to medication toxicity.

Segal [272] reviewed and compared (benchmarked) published studies looking at the economic, clinical and psychosocial outcomes of home infusion therapy. He pointed out that cost savings had not been reported in a systematic way from study to study (i.e. not comparing like with like) but overall the cost of home infusion therapy was lower compared to hospital treatment programmes. The overall direct charges to patients were often higher due to the fact that third-party payers may not cover the full cost of this type of treatment. The clinical outcomes were comparable to those achieved in hospital. Complications related to catheter care were common in home therapy but one study found that a larger proportion of patients using home infusion therapy could keep to their dosing schedule compared to hospital patients. Many patients were able to return to work or school but there were also a number of reports of patients refusing home infusion therapy. Levels of psychological stress were reported to be lower at home than in hospital in one study, although another study of TPN patients found that a high proportion of patients had psychological problems in adjusting to home parenteral nutrition. It was concluded that there was a marked bias towards the benefits of home infusion therapy as an alternative to hospital therapy but this should be interpreted cautiously due to the wide variation in the populations of patients studied, patient selection, study site and limitations in study design. A recommendation was made that research standards be developed for the evaluation of home infusion programs and a prospective study with clear definitions of direct and indirect costs and benefits be carried out.

By 1996 the home setting had become the accepted "norm" for many prescribed infusion therapies in the United States [135]. Activities of health professionals

were collectively monitored as "patient-focused functions" and the home care industry had begun to embrace the concepts of TQM and CQI. The challenge was managing change whilst maintaining quality [135].

Hamill [325] looked at measuring quality, outcomes, standards and costs in the home medical equipment (HME) industry. He emphasises the need for standardised assessments, methods and analyses performed on data and advocates the monitoring of clinical outcomes, service outcomes and patient outcomes with the aim of establishing a service benchmark that can be used to determine appropriate standards for providers and which can be used for internal quality improvement. The creation of a national reference database focused on the home health business is mentioned (called "HOMEcare databank" and sponsored by the National Association for Medical Equipment Services (NAMES)). Hamill also recognised the need among home care providers for a nationally standardised, reliable, valid patient satisfaction tool which would benefit both payers and providers. A tool was being developed by the Picker Institute with a grant from the Commonwealth Fund of New York.

McKeon [44] discussed his experience of benchmarking in Home Health Care Agencies pointing out that the key to benchmarking is understanding the composition of the benchmarks and making sure that like is compared with like. Cost per visit, the average number of nursing visits per day, and percentage of patients discharged to home health by Diagnosis Related Group are cited as examples of benchmarks used within the home health industry. They are generally available because they form part of the regulatory data collection process or because they can be extrapolated easily from data collected within the agency but do not provide good benchmarks because of their lack of homogeneity. McKeon points out that the home infusion industry has difficulty in defining common terminology and standards for the delivery of care and calls for the development of industry wide indicators that include common activities, activity attributes and measures. In the mean time he suggests the development of an activity-based management system, which would at least allow the development of agency specific standards to evaluate operational results with respect to strategic goals. The use of external benchmarking from outside the

home care industry was advocated, the examples given were organisational rather than clinical in nature. Benchmarks should be relevant, easy to calculate, evaluate internal and external customers' perceptions and support continuous quality improvement efforts. Classification by patient problem can be used to ensure greater homogeneity of benchmarks and results of patient surveys can be added to the performance measurement process. Use of the balanced scorecard, another tool developed in manufacturing industry and adapted for use in quality initiatives in health was suggested (described later in section 4.1.5.3.)

The importance of outcome standards was discussed by Seignemartin [45] citing the fact that infusions are given in alternate sites even campgrounds as one reason for needing to monitor outcomes along with cost containment, expectations of patients, accreditation and performance improvement. She defines an outcome indicator as a tool used to measure the result of the performance of a function and gives examples of five outcomes indicators developed in the setting of home infusions. These were a patient discharge survey, infection rate, adverse drug reactions, unscheduled readmissions to hospital and a log of interventions. It is pointed out that the challenge is not to collect information but to find standardisation for collection to enable benchmarking with other institutions and with national averages.

Rosenheimer [326] reports an infection control benchmarking exercise involving four home health agencies. Standard definitions for symptomatic urinary tract infections in patients with urinary catheters and for bloodstream infections in patients receiving intravenous therapy were agreed and identical data and methods for calculating infection rates were developed to ensure homogeneity of the benchmarks. The primary aim for each company was to collect baseline data about its infection rates and use these in the future to detect problems and trends. The secondary goal was to make infection control benchmarking between the agencies possible. Limitations in reporting incidence of blood stream infections were noted as one site had an extremely small number of device days so one infection resulted in a high incidence rate.

Kunkel [46] looking at outcomes of home antibiotic infusions defined an outcome as an indicator of the results of a process which is related to the content and delivery of healthcare and is used to determine the best approach to that care. He notes that outcome data must be measurable but are not useful as indicators until they are transformed through analysis. From the financial perspective good outcomes are not enough, the extra cost of achieving the good outcome must be factored in using the concept of value. Kunkel divides outcomes in home antibiotic infusions into macro outcomes (organisational performance, clinical effectiveness, service quality, patient satisfaction, appropriateness of care, response to treatment and cost and efficiency) and micro-dimensions (adverse events, clinical success of therapy, readmission, interventions, functional status, patient/family well-being, achievement of therapeutic goal, cost). The most important question he recommends asking is "Do the benefits of tracking and analysis outweigh the costs of collection and analysis?". It is suggested that tools for data collection are standardised and data element defined. Once the data have been validated they can be used for both internal and external benchmarking.

Birnbaum and Tang [279] developed a model for incorporating the cost of adverse outcomes into overall cost of home infusions for use by purchasers of home infusions. Using this model showed that vendors who appeared to be lower cost were actually higher cost when the cost of remedial care for adverse outcomes was taken into account.

In the USA during the 1990s benchmarking and performance measurement companies have emerged who collect data anonymise it and produce reports which compare outcomes with companies of similar case mix, load and size [273]. They specify criteria and definitions for the data collected to try and ensure that like is compared with like. In any industry there are companies who perform better than others. Cain [273] specifies what to look out for when choosing a performance measurement company and comments that the ability to not only measure yourself but also to compare yourself with other providers is very beneficial and allows identification of areas that need work. She gives an example of an increase in occluded venous access devices that required the use

of urokinase and an improvement that was demonstrated after the implementation of a new flush technique and a needleless system.

With the introduction of Managed Care in the USA, companies seeking contracts not only need to be accredited but also the company is required to be involved in a national outcomes program [46, 273]. Outcome measurement is now a requirement of Medicare, JCAHO and NCQA (National Committee for Quality Assurance) accreditation and is increasingly becoming a requirement for all programmes. The American Society of Health Systems Pharmacists promote a "software solution for the entire home infusion office" called iv-ease Home Infusion designed to help organisations to meet the Joint Commission standards for home health care organisations. The commercial nature of performance measurement of home care companies in the USA has meant that there have been few published studies showing the development of benchmarks as performance indicators and it is difficult to obtain detailed information on data collected as it is no longer in the public domain. In England service specifications are often not set and contracts are not monitored [284] by purchasers. There are no performance measurement companies specialising in the home infusion market and there are no recognised performance indicators or benchmarks for the home infusions.

4.1.5 Methods of Benchmarking

There are many ways to go about a benchmarking project. The method used must be adapted to suit the goals of the project being undertaken and the organisations involved. Benchmarking is a structured tool and although there are numerous different methods reported in the literature they all follow the same sort of approach, the Deming [327] plan, do, check, act cycle.

Given the success of Xerox in employing the benchmarking process the Xerox Ten-Step Benchmarking Process is probably the most often quoted (Figure 4.3) [292, 294, 303]. Camp and Tweet explain how the Xerox approach can be adapted to use within health care [303].

Zairi [294] gives details of the processes developed for benchmarking in a variety of organisations. Kodak have a ten step benchmarking process which broadly follows the lines of the Xerox approach, the Post Office Counters method is a little different and is divided into process and documentation. The Australian NRMA have developed an international best practice model flowchart and Texas Instruments Europe have their own 10 step approach which is divided into the four phases used by Xerox of planning, analysis, integration and action. IBM has been a leader in quality concepts and IBM, Rochester won the Malcolm Baldridge National Quality Award in 1990. IBM, Havant's four phases are organisation and planning, data collection, analysis and action with a 14-point flowchart demonstrating their benchmarking process. Rover simplified the competitive benchmarking process down to define five key stages, plan, investigation, measure and analyse, communicate findings, plan and implement action, review and calibrate.

Figure 4.3, Xerox Ten Step Benchmarking Process

Phase 1 –Planning

1. **Select a subject to benchmark**

Determine the purpose

Recruit the team

Determine the measurements

Determine the scope and constraints

Obtain support of major stakeholders

2. **Identify the best practitioner(s)**

Prepare a list

Select the benchmarking partners

3. **Determine the Data Collection Method and Collect the Data**

Prepare a list of questions

Answer the questions for your own operation

Search for data in existing studies

Review processes for collecting new data

Select process(es) and develop guidelines

Determine who will conduct data gathering

Review legal, ethical and protocol requirements

Collect data using process guidelines

Phase 2 - Analysis

4. **Determine the Current Gap**

Tabulate the data

Analyse data against the purpose of the study

Determine the benchmark

Determine the gap

Determine the general reasons

Determine specific drivers and practices

5. **Project Future Performance**

Identify assumptions used in projection

Project the gap

Phase 3 - Integration

6. **Communicate the Results of Analysis**

Understand your audience

Determine method of communication

Organise your analysis

Obtain acceptance from stakeholders

7. **Establish functional goals**

Identify current goals

Determine what changes could and should be made

Revise your gap projection

Obtain commitment to changes

Revise functional goals

Phase 4 -Action

8. **Develop action plans**

Prepare action plans

Organise your plan

Obtain functional buy-in

9. **Implement, plan and monitor results**

Implement action plans

Monitor results

10. **Recalibrate benchmark**

Identify appropriate time frame

Repeat steps 1-9.

4.1.5.1 Selecting the process to benchmark.

It can be seen from all of the above processes that the first step is selecting the process to benchmark. There are various techniques employed to help decide a subject area. The criteria for selecting the subject are that it should be of strategic importance to the business and improvement in an area that will make a significant contribution to overall business results [293]. Codling [293] uses a series of five questions to identify processes to benchmark:

1. Which business are we in?
2. What must we do to remain in business?
3. What must we do to be really successful in our business?
4. Which single factor would make the most significant improvement to our customer/supplier/employee relationships?
5. Which areas, if improved, would make the most significant contribution to our bottom line results?

Management's task is to gain consensus on which processes should be selected. A common sense approach is required alongside any system used to help identify an area where benchmarking could have the greatest impact.

Critical success factors are those characteristics, conditions or variables that have direct influence on customer's satisfaction with the output, product, service of specific business processes and, hence are critical to the success of the entire business. They represent measurable or observable aspects of business processes, which when performed well, result in the continuing growth and success of a business. In short, they are the critical few factors that have the most impact across the entire business system [295] MacDonald shows a method whereby critical success factors can be correlated with critical processes so that those processes which by their improvement would have greatest impact on the critical success factors can be identified for benchmarking [296]. Bullivant uses a table of critical success factors against barriers to success; it is easy to express a commitment to critical success factors but do nothing to make them happen. Success will not be achieved until the barriers have been removed [302].

The European Foundation for Quality Management (EFQM) has developed a model for identification of key processes or practices to be benchmarked. It involves a scoring system based on five sets of criteria known as 'enablers' followed by four criteria that address the 'results' obtained as a consequence of the use of these 'enablers' [294, 296].

Zairi [298] gives an example of Ramirez and Loney's work using critical factors of TQM to check whether the philosophy of TQM was transferable to the UK NHS.

4.1.5.2 Defining the process.

One of the next steps is to make sure that the way the organisation works and the current processes used are fully understood. This involves process analysis and is extensively discussed by Hunt in relation to reengineering [328]. It is important to find out what really happens not what people say happens or think should happen. What people do and what they say they do are almost never the same [288] so it is important to observe a process when mapping it for the purpose of a benchmarking study. Bullivant [290] starts by defining the boundaries of the activity and clarifying the desired outcome of the activity to be benchmarked. The next step is to map the current process (process mapping). This can be done using process flowcharts, flow diagrams, cause and effect (Ishikawa) diagrams, Pareto charts, or more complex methods such as CASE tools and simulation tools [328, 329].

The subject of process mapping in health care is addressed by Corbett [330] who points out that the first obstacle in benchmarking is understanding how work is currently performed. She advocates flowcharting current processes to build a frame of reference to use when talking to benchmarking partners. First a simple six to ten box linear flowchart is drawn to outline a process. A connection chart can be used to show how different departments interact then a cross-functional flowchart to show who is working together at each stage of the process. Other information can be added to this for example, the length of time each process takes justification of the cost of procedures, customer satisfaction and copies of

relevant policies and procedures. Areas that seem to be the source of inefficiencies can be broken into microlevel charts so that the process may be followed more closely. Flowcharts can also be used to identify what is going well so that these processes can be retained when the process is redesigned.

4.1.5.3 Benchmarking Methods Used in Healthcare

An example of a benchmarking model used for a benchmarking process in health care is the Baxter Benchmarking Model (Figure 4.4) incorporating 15 essential steps to successful benchmarking and divided into the preparation phase and the benchmark analysis phase.

Figure 4.4, The Baxter Benchmarking Model

Preparation Phase	1. Define goals
	2. Define processes
	3. Choose what to measure
	4. Commit resources
Benchmark Analysis	6. Identify sources of data
Phase	7. Collect data
	8. Translate data to common format
	9. Identify best level of achievements, that is, the benchmark
	10. Identify differences between your organisation and the benchmark
	11. Identify factors driving the differences
	12. Verify the results
	13. Present the results and conclusions
	14. Agree on action steps
	15. Form task forces to implement action steps

A British example is that of Leicester Royal Infirmary who have developed their own benchmarking process heavily inspired form the Rank Xerox methodology (Figure 4.5).

Figure 4.5, The Benchmarking Process at Leicester Royal Infirmary

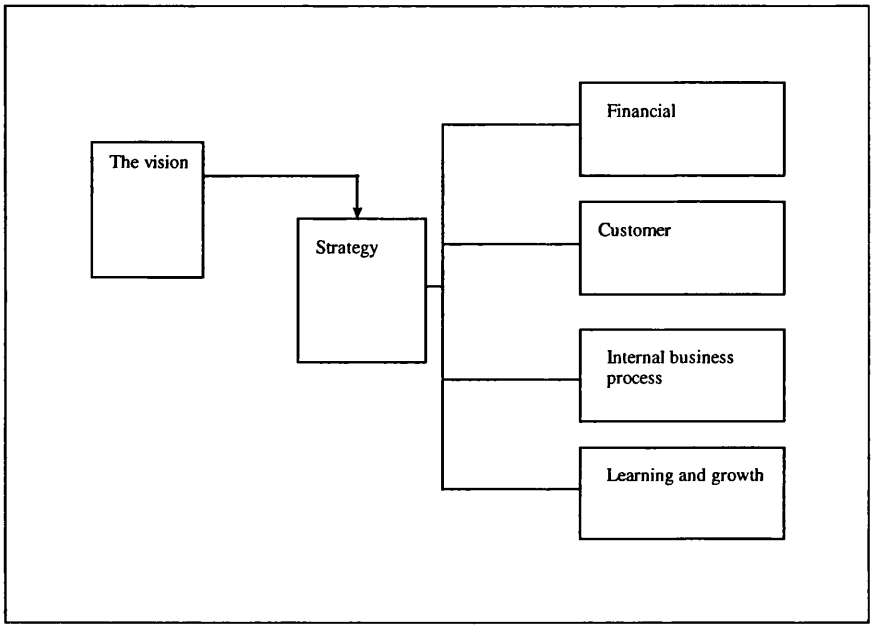
Organise and Plan	Subject area selection
	Specify process
	Partner selection
	Data requirements
Analysis	Collect data
	Determine gaps
	Establish process differences
	Set targets
Action	Improvement plans
	Implement
Review	Review progress
	Plan next cycle of benchmarking

It can be seen from the examples given above that the general structure of a benchmarking process varies little, but once this is broken down further there is huge variation in the way the steps are achieved and indeed achievable in different industries.

McKeon uses benchmarks, performance indicators and the balanced scorecard as a way of evaluating organisational results and continuous quality improvement efforts (Figure 4.6). The balanced scorecard developed by Kaplan and Norton is a way of enabling management to see the breadth and totality of company operations rather than focusing on the attainment of financial goals [288]. McKeon argues that in the past, too much emphasis has been placed on financial indicators as benchmarks and he suggests using the balanced scorecard which encompasses the internal and external customer, clinical and financial results, process improvement and activities designed to expand the agency. Elements which are out of balance can be identified and corrected and decisions can be

made to consider how all the pieces interrelate [44]. Performance measures can be used to benchmark both internally and externally but he stresses the importance of understanding the composition of benchmarks and ensuring homogeneity.

Figure 4.6, The Balanced Scorecard



4.2 Development of a Benchmarking Tool for the Home Infusion Industry in England.

4.2.1 Select a subject to benchmark

This work has so far established from questionnaire surveys that the market for home infusions in this country is highly complex with a heterogeneous group of patients with varied diagnoses receiving different therapies via different mechanisms which are being commissioned in a variety of ways.

The Health Authority questionnaire identified, mostly in the qualitative data collected, concerns about the lack of monitoring of the quality of care received by patients or even a basic monitoring of adherence to service specifications [284]. Further questions regarding monitoring of the quality and patient outcomes of HTHH in the Trust and commercial home care provider surveys raised further concerns in that in many cases service specifications had not been set [331]. This was particularly true when the home infusion service was being provided directly by a NHS Trust and was not being purchased via the HA under EL(95)5 [41] mechanisms. Commercial providers of HTHH reported that they most often contracted directly with NHS Trusts and that this was often on a one-off, ad-hoc basis with little or no monitoring of the service they provided by the purchaser.

Using grounded theory this research has identified the urgent need for a tool to be developed to facilitate quality monitoring, help set service specifications and benchmark home infusion services to learn from the processes of those achieving the best results. Effective and thorough monitoring of quality is the first step, which leads to continuous quality improvement usually via audit, used to improve internal outcomes and then benchmarking to achieve "best practice".

4.2.2 Aim

The aim was to develop a tool which could be used for this purpose.
An outline of the development of the benchmarking tool is shown in Figure 4.7 and will form the basis of this chapter. A copy of the tool developed is enclosed in Appendix 25, on a compact disk, in Microsoft Access ® Version 97, Windows® 98.

4.2.3 Determine the Purpose

The purpose was to develop a tool which could be used;

by purchasers to

- facilitate cost-effective purchasing and ensure added value. It has been shown that providers who submit lower cost tenders for contracts but provide a lower quality service cost more due to the treatment of complications [279]
- set reasonable minimum service specifications to achieve higher goals in quality of care received by patients and to ensure equity of care for patients across the country in line with the government's agenda [2-5, 61, 62]
- allow monitoring of contracts and adherence to service specifications.
- achieve clinical governance targets by using data for continuous quality improvement [62]
- compare the cost and clinical outcomes of home infusions with those of treating patients as inpatients to ensure that patients do at least as well at home

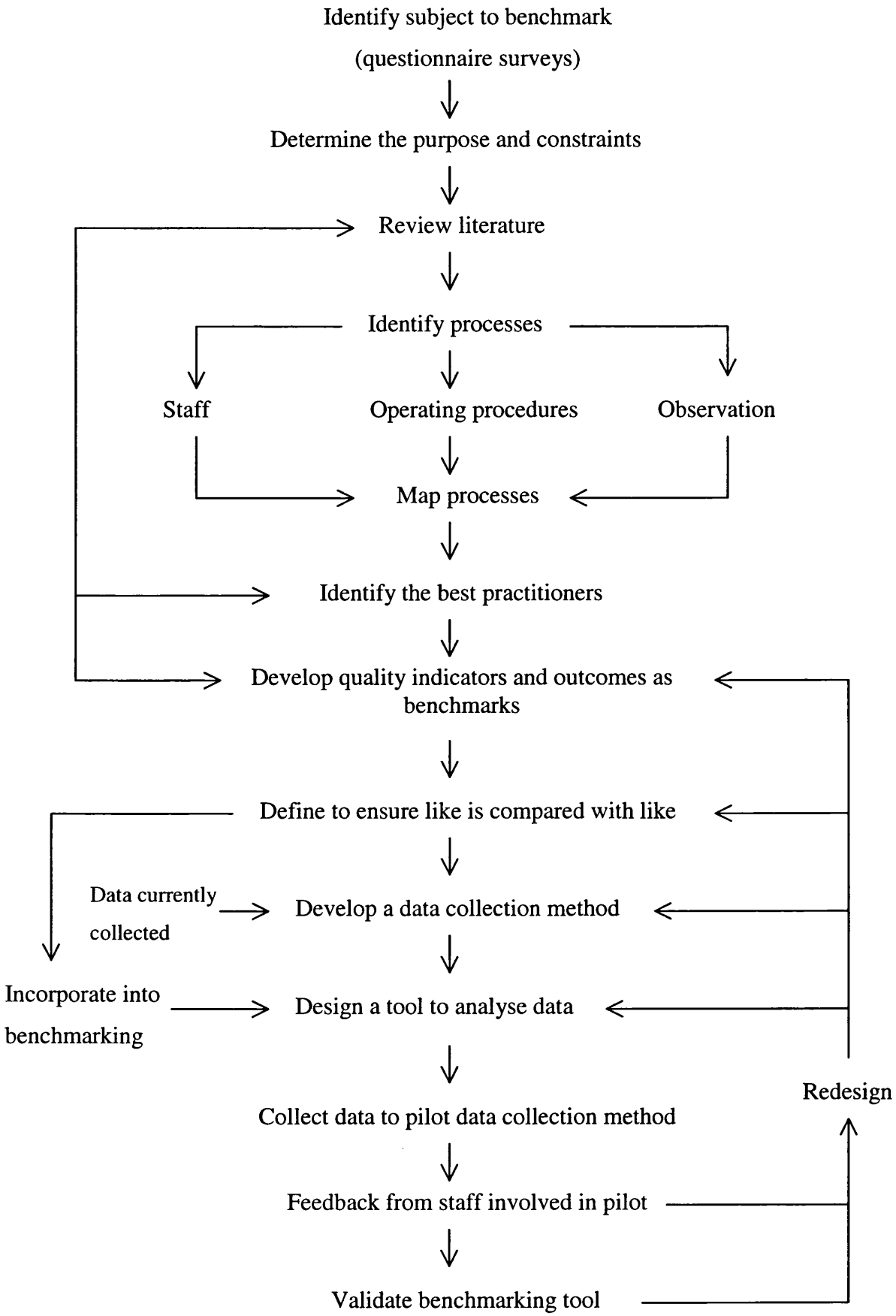
and by providers to

- compare outcomes and performance indicators with others to determine differences and to learn from the processes employed by others how to adapt their own practice to achieve better outcomes for patients
- identify trends in both clinical and non-clinical outcomes which can be used to identify and address problem areas
- identify training needs.

- make treatment decisions such as which patients on which drugs do best with which sorts of infusion device and which IV access device
- improve information given to patients when they commence therapy by looking at the most common problems patients have contacted health professionals about and adapting information provided to suit patients' needs
- improve communication between health care professionals about a patient by having all information collated and accessible to those who need it
- evaluate the impact of education/staff training/patient training and changes in process.

Much if not all, of the data required to do this is currently collected. It is stored on paper, often in prose, in different departments or organisations. The idea of developing a database was to store the information in a way that would allow it to be used to improve patient care. Both from collating the data so that it is available to all staff looking after the patient and by learning from the data by using it in continuous quality improvement and clinical governance initiatives.

Figure 4.7, Development of the Benchmarking Tool



4.2.4 Determine the Constraints

A difficulty always evident when looking at home infusions as one entity is that the patients, their diagnoses and therapies are diverse and outcomes that are important in one group e.g. maintenance of or increase in weight in a HPN patient, are not as relevant to other therapies. The same can be said for specific indicators of outcome of antibiotic treatment in cystic fibrosis patients such as respiratory function tests. Therapy or diagnosis specific indicators of clinical outcome are perhaps more valid than general home infusion indicators and would be the next stage in development of this tool.

These differences in patients and their therapies also means that the processes involved in their care can be very different, for example a TPN patient will almost certainly commence their therapy in hospital but a patient receiving a home chemotherapy infusion may well never be admitted as an inpatient and receive all of their training, care and support in outpatients or in a specialist cancer unit. A cystic fibrosis patient receiving antibiotics may be under the care of a district nurse, or a home care company nurse or an outreach nurse from the hospital or a combination of these. Information required about these patients will be different but there are common themes and so a tool was developed to monitor common performance indicators and benchmarks.

From piloting the benchmarking tool it was found that one of the major constraints to benchmarking and outcomes monitoring of home infusions in England is that the data are stored separately by different individuals using different mechanisms. Information is initially stored by the GP in both written and electronic notes, then by the hospital specialist in hospital records. Different departments in hospitals keep separate records such as pharmacy, physiotherapy, and laboratories, and similarly home care companies and others that they contract with keep separate records about patients. It was found that even within one home care company there are often multiple records for one patient regarding different aspects of their care. The storage of information is centred around the providers rather than being centred around the patient. It is currently almost

impossible to collate all of the information stored about one home infusion patient. It is hoped that this will improve with the introduction of one NHS number for patients and the drive to achieve computerised patient records which can be accessed at different levels by all health care professionals looking after a patient. The potential year 2000 problem caused many hospitals to install new computer systems with greater compatibility between systems and greater access to patient records. The recent NHS Plan [5] has reinforced the push towards electronic records and electronic prescribing in both primary and secondary care.

All performance indicators and benchmarks have limitations and should be used with these in mind. A tertiary centre may well be treating patients with poorer prognoses to start with who may be more susceptible to blood stream infections or other complications. It is beyond the scope of this work to refine outcomes incorporating further factors to make them more specific to particular patient groups. At present there is very little or no data to compare. The benchmarks will need to be refined to ensure that like is truly compared with like.

4.2.5 Review the Literature

The literature was reviewed (3.1 and 4.1) in order to learn from the experience of others in benchmarking services, to determine indicators that have been successfully used in outcomes monitoring of home infusions and to identify "best practice", not only from home infusions but wherever best practice occurs, for example incidence of line infections may be better in an inpatient setting.

It was found that benchmarking of health services in general and more specifically benchmarking of home infusion services is far more developed in the USA than in the UK. In the UK clinical audit has been widely adopted as the means for continuous quality improvement but has limitations in that it only measures, usually small, improvements internally and does not pick up the fact that the outcomes when compared with others may be completely unacceptable. Using benchmarking, processes can be changed by learning from what has been demonstrated to provide the best outcomes elsewhere.

Although benchmarking has been adopted to some extent in the NHS [287, 290, 294, 298, 302, 319, 320] the only benchmarking of the provision of home infusions in the UK that was found was in the provision of home parenteral nutrition. Mughal and Irving [7] found an inverse relationship between catheter-related sepsis and the treating team's experience with HPN. Richards *et al* [213] compared the results of 56 studies, 37 from the USA and the rest from Europe, to look at the patient experience of home parenteral nutrition. They reported a weighted average catheter sepsis rate of 0.34 episodes per catheter year, a weighted average catheter occlusion rate of 0.071 episodes per catheter year, an overall rate for central vein thrombosis of 0.027 episodes per catheter year and a range of 0.12-0.61 episodes per catheter year of metabolic problems. It is important to recognise that in these studies it was difficult to determine whether like was being compared with like.

It was concluded from the literature review that in the USA benchmarking of home infusion services has proved a useful tool in improving patient outcomes and that some of the experiences in the USA may help in developing a benchmarking tool for use in the USA. The review of the literature confirmed that no such tool has been developed for use in the very different health care system in the UK.

4.2.6 Identify and Map the Processes

The researcher mapped current processes used in the care of home infusion patients using standard or agreed operating procedures, guidelines or protocols and observed the process from the decision that a patient may be suitable for home infusion therapy to administration and follow up in the home. Information was elicited from staff involved in the processes.

The first area mapped was that of contracting (Figure 4.8). A contracts manager and Pharmaceutical Adviser of the local Health Authority helped to map the processes involved. This process is specific to South and West Devon Health

Authority, although most HAs would adopt a similar approach as instructed by EL(95)5 [41].

The second process mapped was from the point of view of a person co-ordinating the provision of the home infusion from the patient being in hospital to their maintenance on infusion therapy in their home. There are numerous models for this process involving many staff from secondary care, primary care and commercial providers. It was impossible to map all of the models used and therefore one model was chosen as an example. This was the model where a home care company nurse co-ordinated the process. This involved one person communicating with all others involved and included all of the necessary steps in discharging a patient to their home and maintaining them on a home infusion

Figure 4.8,Contracting Process for Hi-tech Health Care at Home

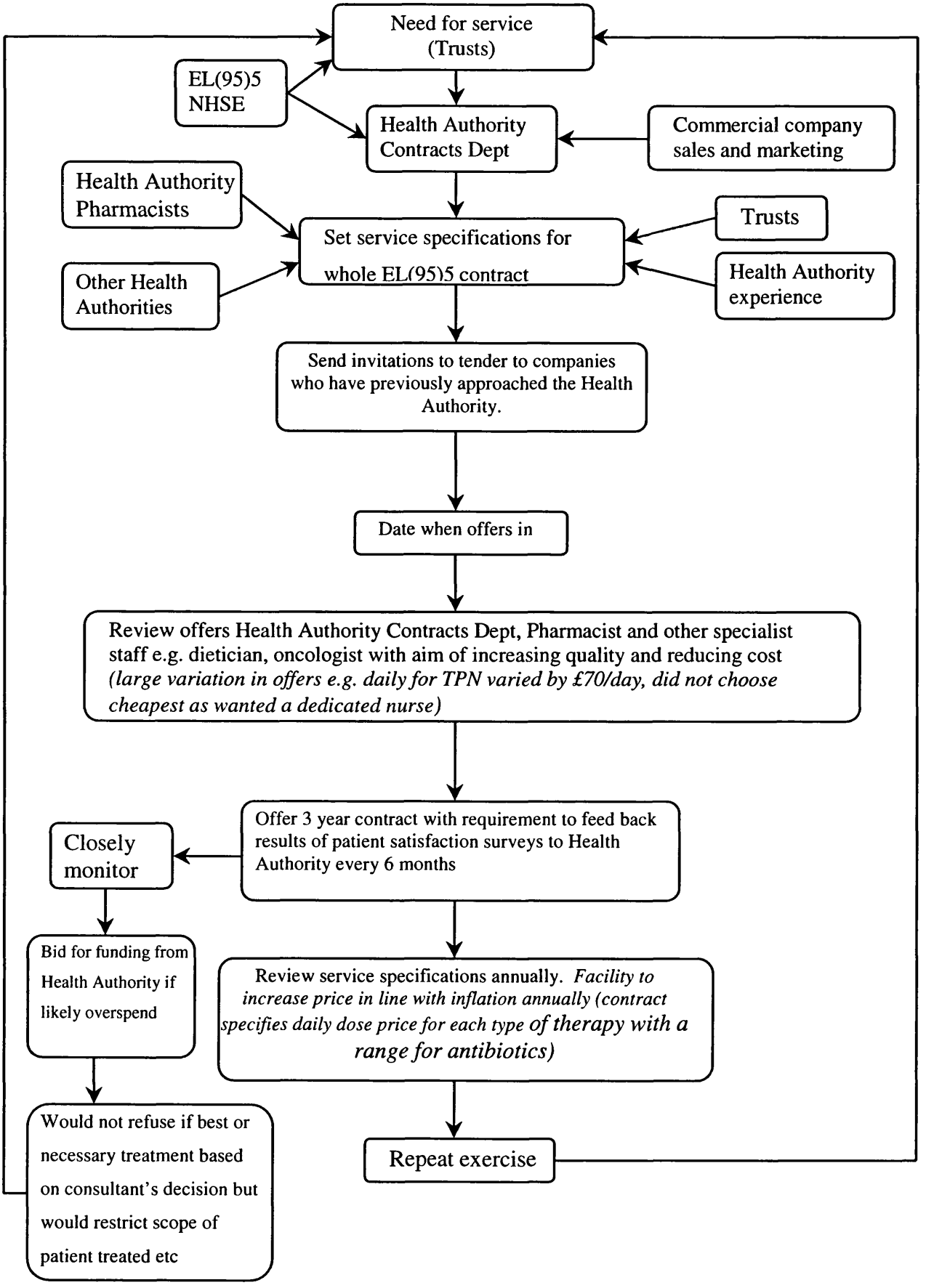


Figure 4.9 maps this process which can be divided into

- Patient selection and suitability of home environment
- Training of patient/carer and other healthcare professionals
- Organisation of equipment, delivery etc
- Co-ordination and communication
- Patient discharge and support and
- Continuing care.

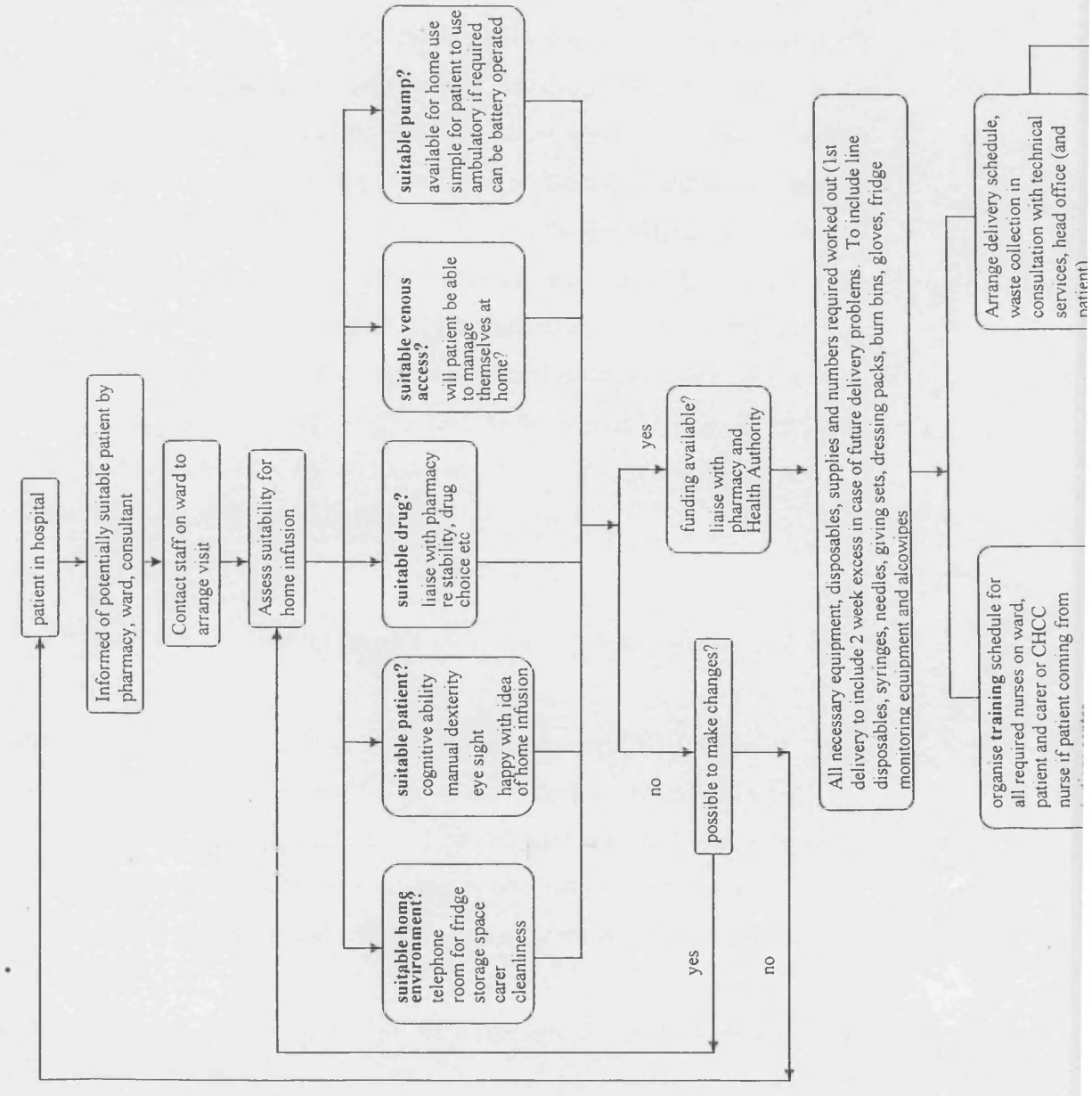
The processes mapped were used in the initial development of the benchmarking tool which will be described in 4.2.10.

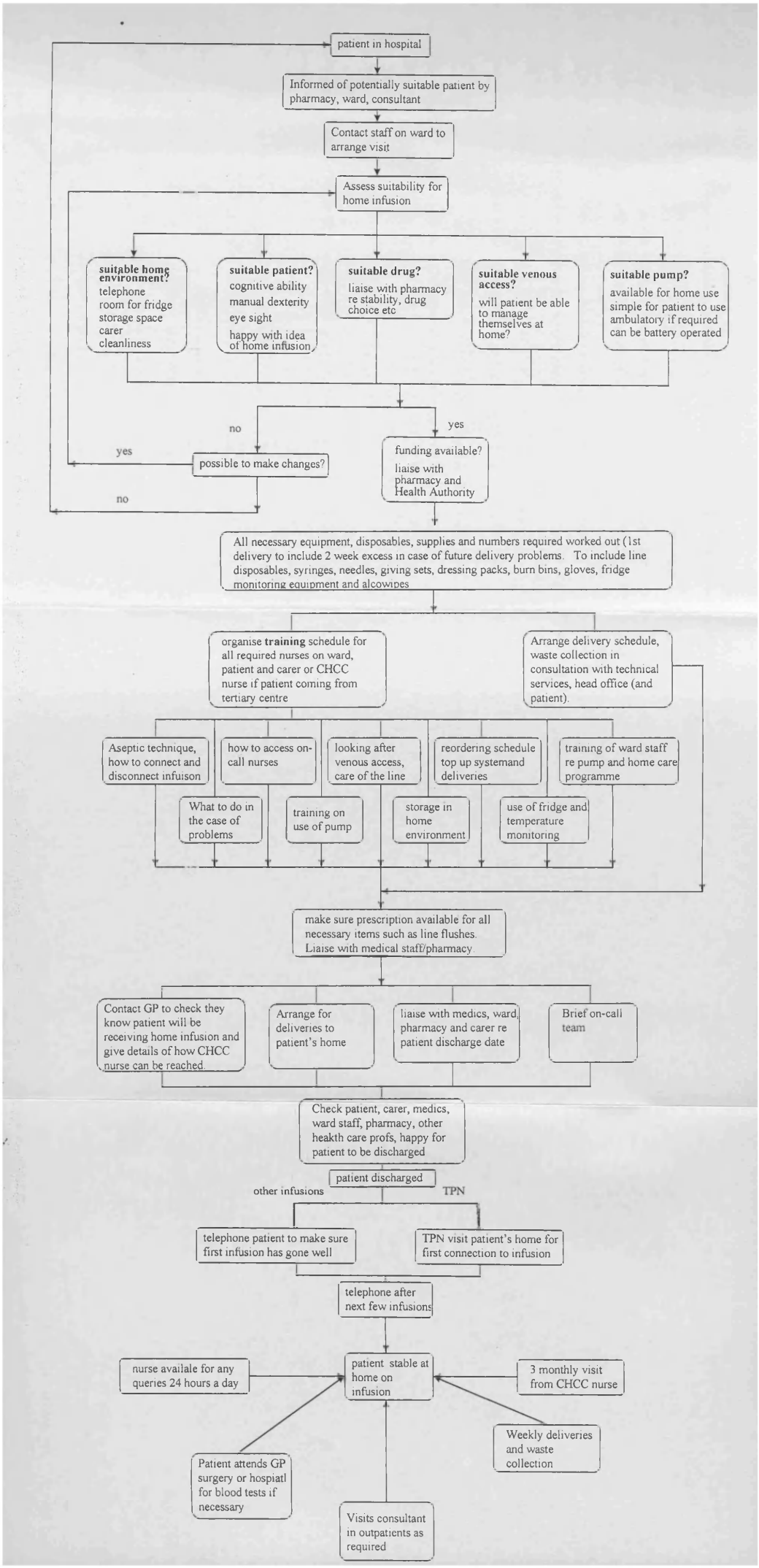
4.2.7 Identify the best practitioners

This project has highlighted the fact that very little information is being collected on the quality of any home infusion services in England. The information that is collected is not routinely shared or used to improve practice within an organisation. Most clinical information is still stored as hand-written notes which makes manipulation of the data difficult.

There has been little or no information published in the UK on benchmarking the provision of home infusions other than TPN. Mughal and Irving [7] published their study in 1986 and Richards *et al* [213] systematically reviewed the literature in 1997 as previously discussed. St Marks Hospital in London and Hope Hospital in Salford are two major tertiary centres who both provide TPN to large numbers of patients at home. They have been comparing empirical data such as incidence of line infections and catheter occlusion rates for some years [332]. Hope Hospital have published papers including information regarding their line infection rate and these are one of the few sources of benchmarks available in England [209, 333, 334]. It has also been reported that North Staffordshire Hospital has designed and validated outcome measures for a home IV service for cystic fibrosis patients in North Staffordshire [146].

Figure 4.9, Processes Involved In Providing A Home Infusion Service From The Perspective Of A Home Care Company Nurse




patient in hospital
Informed of potentially suitable patient by pharmacy, ward, consultant
Contact staff on ward to arrange visit
Assess suitability for home infusion
suitable home environment? telephone room for fridge storage space carer cleanliness
suitable patient? cognitive ability manual dexterity eye sight happy with idea of home infusion
suitable drug? liaise with pharmacy re stability, drug choice etc
suitable venous access? will patient be able to manage themselves at home?
suitable pump? available for home use simple for patient to use ambulatory if required can be battery operated
no
yes
yes
possible to make changes?
funding available? liaise with pharmacy and Health Authority
no
All necessary equipment, disposables, supplies and numbers required worked out (1st delivery to include 2 week excess in case of future delivery problems. To include line disposables, syringes, needles, giving sets, dressing packs, burn bins, gloves, fridge monitoring equipment and alcowipes
organise training schedule for all required nurses on ward, patient and carer or CHCC nurse if patient coming from tertiary centre
Arrange delivery schedule, waste collection in consultation with technical services, head office (and patient).
Aseptic technique, how to connect and disconnect infuison
how to access on-call nurses
looking after venous access, care of the line
reordering schedule top up systemand deliveries
training of ward staff re pump and home care programme
What to do in the case of problems
training on use of pump
storage in home environment
use of fridge and temperature monitoring
make sure prescription available for all necessary items such as line flushes. Liaise with medical staff/pharmacy
Contact GP to check they know patient will be receiving home infusion and give details of how CHCC nurse can be reached.
Arrange for deliveries to patient's home
liaise with medics, ward, pharmacy and carer re patient discharge date
Brief on-call team
Check patient, carer, medics, ward staff, pharmacy, other heakth care profs, happy for patient to be discharged
patient discharged
other infusions
TPN
telephone patient to make sure first infusion has gone well
TPN visit patient's home for first connection to infusion
telephone after next few infusions
nurse availale for any queries 24 hours a day
patient stable at home on infusion
3 monthly visit from CHCC nurse
Weekly deliveries and waste collection
Patient attends GP surgery or hospiatl for blood tests if necessary
Visits consultant in outpatients as required

There is some information available from the USA on line infection rates [335] and incidence of other problems in home infusions such as number of out of hours calls, however the data is often now collected commercially and is not in the public domain [30]. It can be seen from the Table 3.1 which compared catheter sepsis rates in patients receiving home parenteral nutrition that most of the data from the USA is from the late 1970s and early 1980s. The health care system is very different to that in the UK but, if the outcomes achieved are better than those being achieved in England, the processes and practices adopted in this country need to be examined and lessons learned from our colleagues across the Atlantic. Presently there is a dearth of information from England on the quality and outcomes of home care programmes. Much of the published information states that complication rates are low but these are rarely quantified [336]. Melville *et al* [30] working in paediatric gastroenterology at Great Ormond Street Hospital, London, compared catheter survival and sepsis rates in the same 20 patients receiving TPN in the hospital and the home care setting. They found a significant reduction in the rate of sepsis and a similar improvement in line survival at home compared to hospital.

4.2.8 Develop quality indicators and outcomes as benchmarks and define them.

The literature on outcomes monitoring was studied particularly looking at outcomes developed in the home infusion industry (2.3.4.1.1) and potential complications of IV therapy [337]. In order that extra work was minimised the benchmarks were developed from data already routinely collected and the benchmarking tool was designed with the purpose of minimising data entry.

Outcomes cannot be directly altered but are a function of structure (relating to for example organisation, personnel, management, equipment, records) and process (how these are used). By changing or developing aspects of structure and process outcomes may be altered. Structural, process and clinical outcomes are all useful benchmarks and should be included in a benchmarking tool.

4.2.9 Clinical Outcomes

(N.B. Before reading further go to Appendix 26, this will take you through opening the database in Appendix 25 and gives working examples which will be referred to through the remainder of this chapter.)

From the literature and local experience a list of clinical problems associated with home infusions was drawn up [30, 114, 337-340]. This list was sent to other providers of home infusions in England both commercial and non-commercial for comments and was adapted based on comments received (Table 4.1).

Table 4.1, Definitions of Clinical Problems Stored on the Database

Problem	Definition
allergic reaction	characterised by such symptoms as itching, rash and shortness of breath
anaphylactic shock	characterised by such symptoms as swelling, constriction of bronchioles, heart failure and circulatory collapse
blood stream infection	where a recognised pathogen is isolated from a blood culture which cannot be related to an infection at another site (making the assumption that no culture would be done without symptoms).
catheter migration	movement of tip of catheter to site other than that which was intended and where it was originally placed
catheter occlusion complete type A	unable to flush line or draw back any blood, unblocked by flushing without the need for urokinase, alcohol etc
catheter occlusion complete type B	unable to flush line or draw back any blood, unblocked with urokinase or alcohol
catheter occlusion complete type C	unable to flush line or draw back any blood, line remained blocked despite all attempts to clear it, had to be removed and replaced
catheter occlusion partial	one way blockage, or blockage which prevents normal infusion of fluid
depression	Either patient complains of depression or symptoms of depression or this is observed by staff
extravasation	leakage of drug/infusate outside of the vein
therapeutic failure	therapeutic failure e.g. therapeutic failure of an antibiotic, temperature not resolving after 48 hours treatment, infection not responding to antibiotics

infusion phlebitis grade 0	No pain, erythema, swelling, induration or palpable venous cord at or around IV site
infusion phlebitis grade 1	Pain at IV site, no erythema, swelling, induration or palpable venous cord
infusion phlebitis grade 2	Some erythema, swelling or both at IV site, no induration or palapable venous cord
infusion phlebitis grade 3	Erythema and swelling at IV site, induration and palpable venous cord less than or equal to 3 inches above the IV site
infusion phlebitis grade 4	Erythema and swelling at IV site, induration and palpable venous cord greater than 3 inches above the IV site
local infection at entry site	characterised by inflammation, redness, puss at entry site
none	no problems
other	Please specify in box below.
speedshock	flushed face, redness etc due to infusion being infused too quickly.
suspected line complication	Symptoms that may be related to line placement
symptom of disease state	patient complaining of a symptom/problem likely to be related to the underlying disease rather than therapy
thrombophlebitis	thrombus formation at iv entry site

Any database is only as good as the quality of the data entered into it. In order to ensure homogeneity of the data collected it was important to have unambiguous definitions of clinical problems to ensure that like was compared with like. Definitions which had been successfully employed in previous studies were used where possible such as those developed for assessing the degree of infusion phlebitis in patients receiving infusions of amiodarone developed by Hilleman *et al* and used by Cahill [341] and Stonehouse [342].

These definitions are shown on the screen when the problem is chosen from the list in the database (Appendix 25, Clinical Evaluation Form) so that all operators are aware of the definitions (Working Example 1, Appendix 26).

Incidence of adverse drug reactions has been a common outcome measured in home infusion therapy since Barget and Zink [324] noted that it was a necessary addition when developing their clinical indicators in IV home care in 1989. The

classification published by Wills and Brown [343] seemed a useful subdivision of adverse drug reactions in the home care environment particularly as it separates chemical reactions from delivery and pharmacological adverse events. It should be noted that this classification has not been extensively used and itself has limitations. The major limitation for the purpose of its use as an outcome measure in this project is that it does not indicate severity of the adverse drug reaction. After an initial pilot of the database the definitions were adapted to be more user friendly and specific to home infusions (Table 4.2). Adverse drug reactions needed to be included as a separate field as it was thought that it was useful to also record the result of adverse drug reactions such as degree of infusion phlebitis rather than recording this solely as an adverse drug reaction related to the delivery mechanism being used. The nursing staff found this separation easier to work with. The following definitions of severity were developed in conjunction with the staff piloting the database.

- Mild -minor discomfort to patient
- Moderate- requiring treatment to overcome
- Severe-necessitating withdrawal of the drug or dose limiting
- Serious –fatal, life-threatening, disabling, incapacitating or which result in prolonged hospitalisation (Committee on Safety of Medicines and Medicines Control Agency definition).

Table 4.2, Definitions of Adverse Drug Reactions

Adverse drug reactions	Definition
Adverse drug reaction Type A -augmented	Type A (augmented) reaction: Pharmacologically predictable, dose related, improves if medicine withdrawn, common e.g. diarrhoea with chemotherapy
Adverse drug reaction Type C -chemical	Type C (chemical) reaction: Due to irritant action of drug, related to drug concentration e.g. extravasation, pain at the entry site owing to irritant action of drug or excipient, contact dermatitis
Adverse drug reaction Type D -delivery	Type D (delivery) reaction: Caused by method of administration or nature of formulation, improves if medicine withdrawn or method of delivery changed e.g. particles in injections causing thrombosis or blood vessel occlusion, infection at entry site, owing to the opening of a port of entry for bacteria.
Adverse drug reaction Type H -hypersensitivity	Type H (hypersensitivity) reaction: requires activation of immune system, improves if medicine withdrawn e.g. rash with antibiotic
Adverse drug reaction type O -other	Type O (other) Includes adverse drug reactions associated with a micro-organism, withdrawal reactions, reactions which occur only in those who are genetically predisposed, reactions which cause irreversible genetic damage (carcinogenic, genotoxic or teratogenic or reactions whose mechanism not understood.

Information regarding unplanned stopping of the infusion or unplanned visits to the patient or the patient to the hospital and unplanned admissions to hospital were all found to be important negative outcomes to record. They show increased morbidity and increased cost of treating the patients. The database can be used to link these outcomes to other factors to see for instance whether they are more commonly related to a particular type of infusion device, method of administration or method of training the patient. Definitions for these were developed with nurses involved with follow up and continuing care of patients receiving home infusions are shown in Table 4.3.

By virtue of the way that this information is stored on a Microsoft Access® database performance indicators can be developed from any combination of the data input and those included are just examples of the way the data can be used (see section 4.2.13).

Table 4.3, Definitions related to unplanned interruption of infusions, visits and hospital admissions

Unplanned stopping of infusion/visits/hospital admissions	Definition
unplanned home visit by health care professional	visit by health professional to patient in home environment at request of the patient or due to unforeseen problems arising
unplanned or extra visit to outpatients or ward	visits not scheduled in advance but due to problem with home infusion that patient is unable to solve over the telephone or requires reassurance of visit to health care professional
infusion stopped before planned end of course Type A - ADR	infusion ceased or changed prior to end of planned course due to adverse drug reaction
infusion stopped before planned end of course Type B – therapeutic failure	infusion ceased or changed prior to end of planned course due to therapeutic failure, e.g. failure of infection to resolve
infusion stopped before planned end of course Type C –drug admin problems	infusion ceased or changed prior to end of planned course due to drug administration problems
hospital readmission as an inpatient due to condition deteriorating	medical decision to readmit patient due to deteriorating medical condition/need for other forms of hospital care
hospital readmission due to inability to cope with /lack of desire to continue home infusion	decision made by patient carer or professional staff that home infusion not safe or effective or in the best interest of the patient

The following indicators were developed and are made up from both process and clinical indicators of performance of a home infusion program within the limitations already discussed.

a) Incidence of all clinical problems by type of therapy.
b) Incidence of infusion phlebitis (divided by grade) by type of therapy and type of intravenous access device.

c) Incidence of all clinical problems by intravenous access device and benchmarking centre
d) Incidence of all adverse drug reactions (divided into sub-categories) by type of therapy.
e) Incidence of catheter occlusion by type of therapy and type of intravenous access device.
f) Incidence of contacts by patients /carers by therapy group subdivided by main subject of contact.
g) Proportion of out-of-hours contacts over all contacts by patients and carers by therapy group.
h) Information provided to patients/carers by therapy group subdivided into categories of information given.
i) Incoming and outgoing contacts by therapy type for specified categories of information.
j) Incidence of patient/carer enquiries regarding infusion device by type of device and therapy group.
k) Incidence of unplanned patient visits, interruption or stopping of infusion and hospital readmissions by therapy type.

4.2.10 Data Collection Method and Piloting

A Microsoft Access® database (Appendix 25) was used to collect and manipulate data. This software was chosen because it is a readily available Windows®-based programme which is part of the Microsoft Office Pro® package. Many users are familiar with the other software in this package (such as Microsoft Word® and Excel® and PowerPoint®) and there are many shared operating systems which will make it familiar to many users, even if they have no previous experience of operating a database. Conventions such as being able to operate buttons by clicking the mouse on them or by typing the underscored letter were programmed into the database for ease of use.

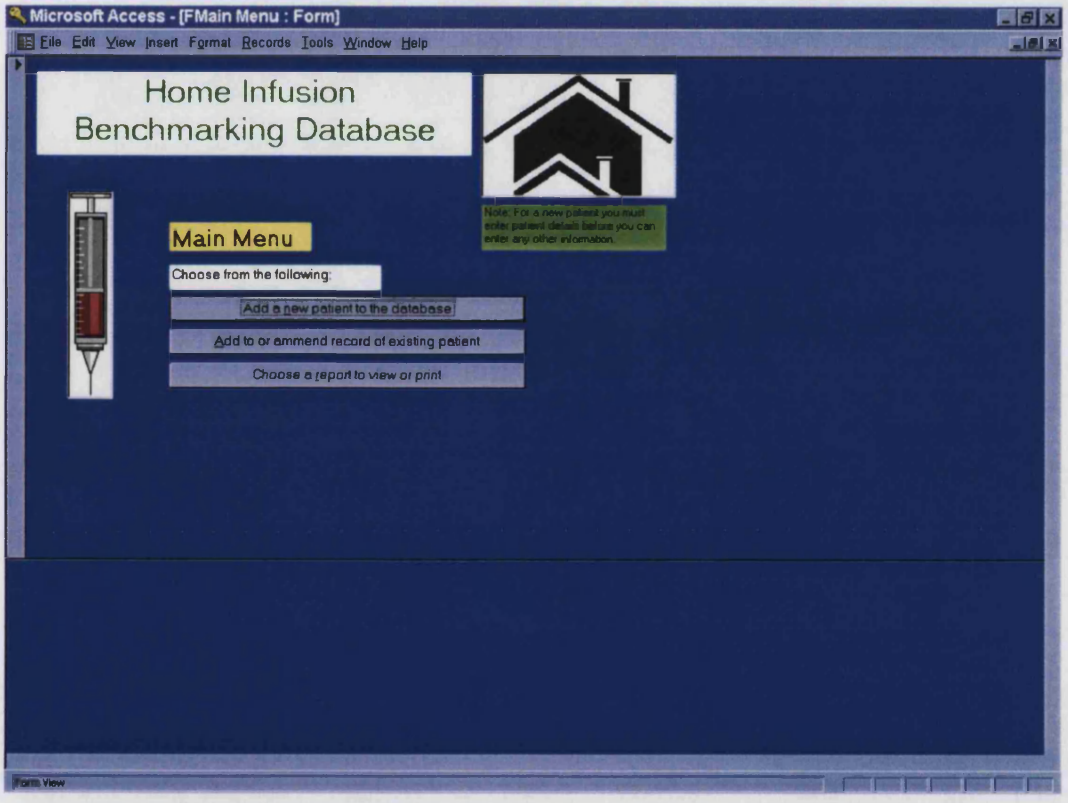
The database was designed so that it would as far as possible, resemble information already collected on paper. User friendly forms were set up with

buttons allowing a user with no understanding of Access to enter and manipulate data by a menu driven system.

4.2.10.1 Main Menu

The main menu (Figure 4.10) form is programmed to open when the database is first opened. It allows the user to choose whether to add information about a new patient onto the database or to amend or add to existing information stored about patients. There is also a button which allows the user to report on current data stored in the database.

Figure 4.10 Main Menu



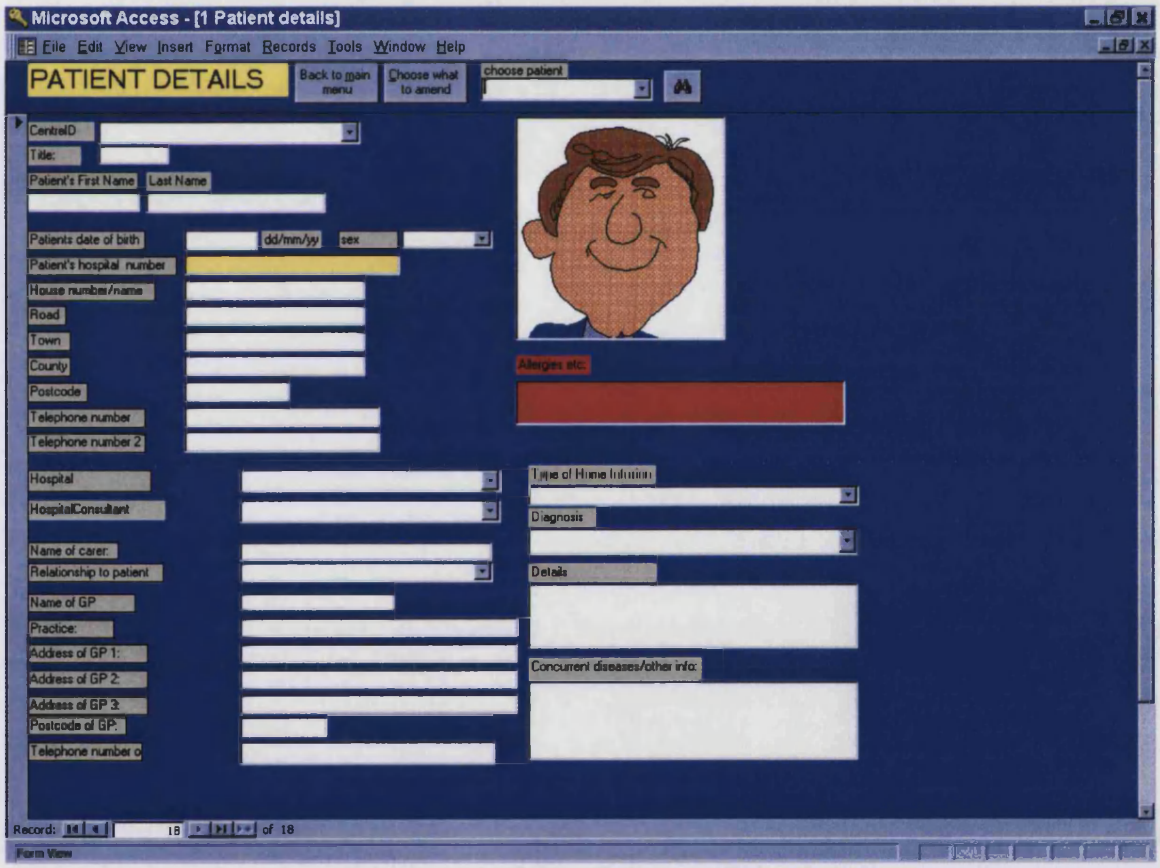
4.2.10.2 Patient Details

The form "Patient Details" collects details specific to the patient which are unlikely to change during the course of the therapy, such as name, address, date of birth etc (Figure 4.11). The database was designed so that this information is only ever entered once and is automatically completed in other forms which refer to it by the computer. Any piece of information known about the patient such as

name, telephone number or date of birth can be used to find the record of the appropriate patient using a find patient button (pair of binoculars).

The patient's hospital number (or ID number used by a commercial company) is used as a primary key to identify patients in all data and for future data manipulation. The database will not allow a primary key to be duplicated as it is used as a unique identifier. If there are patients in different hospitals with the same hospital number the primary key will have to be altered to also include benchmarking centre. With the introduction of NHS number, it will only be possible for one patient to have each number and it would be recommended that this number be used to identify the patient.

Figure 4.11, Patient Details Form



*NB See copy of database on CD (Appendix 25), to scroll down to bottom of page and to see drop-down lists.

To allow ease of data entry drop down list were used so that an entry could be selected from a list rather than typed in each time. This also ensures greater accuracy of data manipulation and for grouping of the data, for example the diagnosis of "rectal cancer" could be written in a number of ways such as "cancer of the rectum" with varying accuracy of diagnosis but if all were entered differently the computer would be unable to recognise them as one diagnosis and group them as such for the purpose of data analysis. It would also be possible in this field to use read codes to store data. These are commonly used both in primary and secondary care in order to group patients by diagnosis. There have been problems in the use of read codes. Clinicians have not been consistent in read code allocation and particularly in general practice it is common for a group of practitioners to agree on a limited set of read codes for use in their system. MIQUEST a software package which extracts clinical data from various GP software packages has highlighted these differences. See Working Example 2, Appendix 26.

It is vitally important to ensure that patient confidentiality is maintained and that the law relating to data protection is followed when storing details of patients in an electronic format. The patient details included in the database (Appendix 25) are fictitious. The database is password protected (password "homeinfusion") and this password protection could be used to allow access to different levels of information to different staff if the database was networked. When the database was piloted some real information was input but access to the information was firmly restricted to the patient's doctor and two research nurses. Two passwords were required to obtain access to the database.

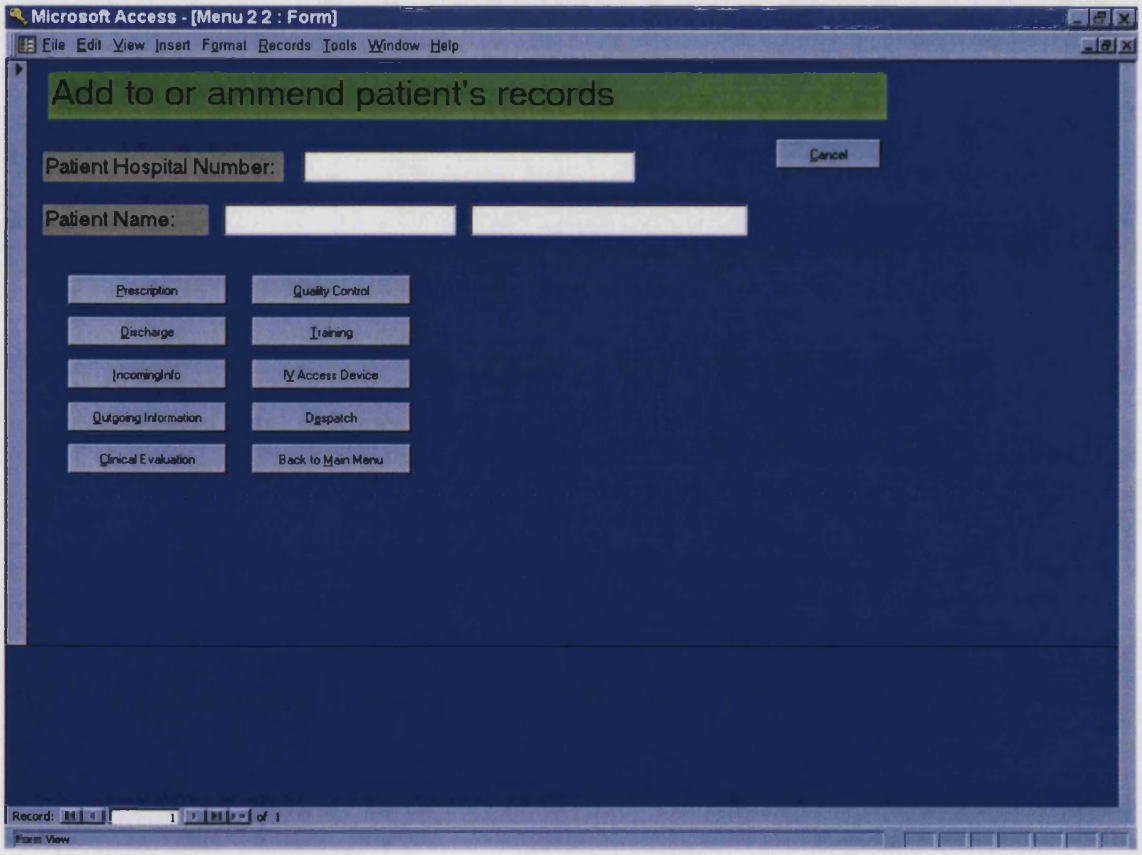
The database is able to function without all fields being filled in but there are some fields on which it relies to sort data and relate it to other information stored in the database. Irrespective of the computer programming there are some fields that it would be illogical not to complete as they are part of the minimum information required such as the name of a drug on a prescription or a patient identifier. If the fields that the computer requires are not completed an error message is shown and the form where the data is being input cannot be saved. It was found on first piloting the database that this became an irritation for the staff

inputting the data as they had to guess which fields these were. These fields on the forms were subsequently coloured yellow so that it was easy for staff to identify what data they were missing.

4.2.10.3 Add To Or Amend Patient Records Form

Once the patient details have been entered or a patient previously entered into the database has been selected a further menu allows the user to select information that they wish to enter (Figure 4.12). Use of this form is covered in Working Example 2, Appendix 26.

Figure 4.12, Menu 2, Add To Or Amend Patient Records

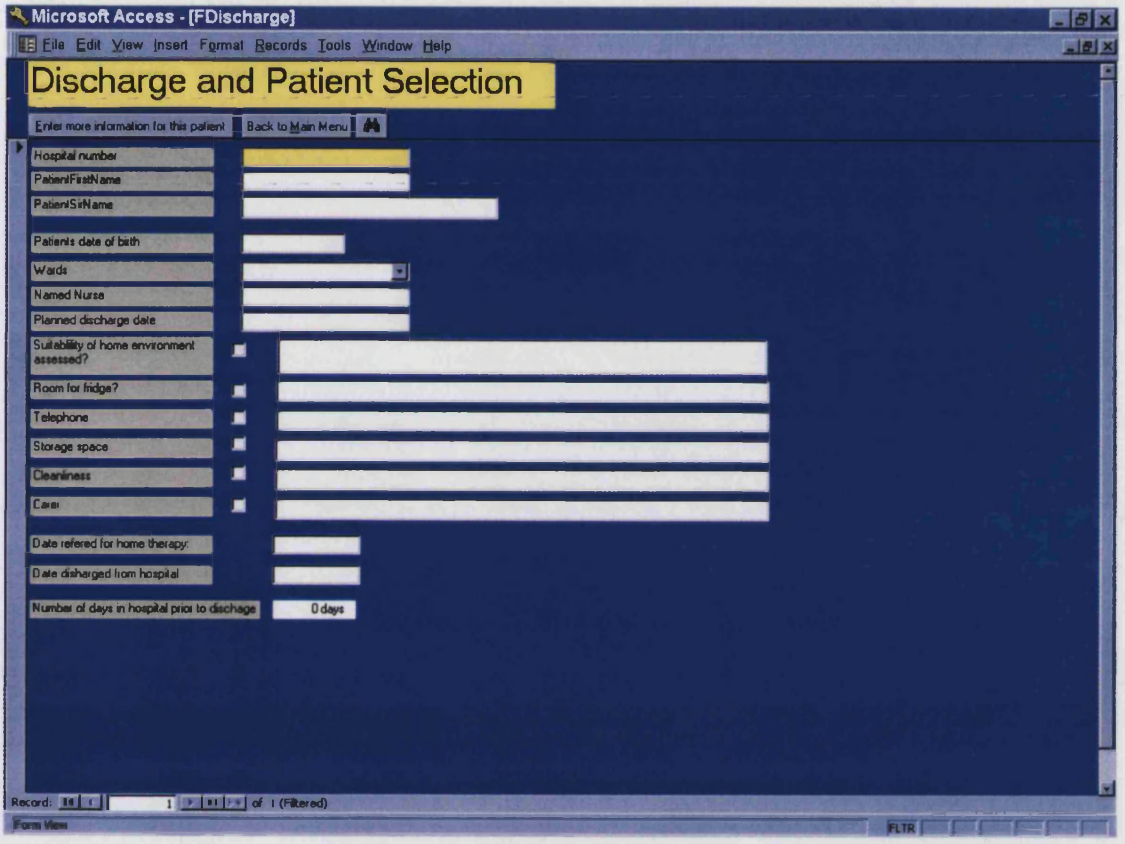


4.2.10.4 Patient Discharge and Selection

The database collects very simple information on patient discharge. It should be noted that patients on home chemotherapy infusions, for example, might not be

admitted to hospital at all. The patient discharge screen is shown below (Figure 4.13) and is used to record suitability of home environment.

Figure 4.13, Discharge And Patient Selection



It is assumed that there is a robust system in place for patient selection and that patients who are entered onto the database are deemed suitable for home care and meet any criteria laid down in the patient selection procedure. The success of home infusion programmes is dependent upon good selection criteria being strictly adhered to [112, 128, 157, 160, 193]. Monitoring of patient compliance with administration of the therapy and adherence to the procedure that they are taught throughout treatment is also important in achieving desired outcomes of treatment [158].

Information collected on this form could be used to monitor how quickly patients are discharged after referral for home infusion and number of days in hospital prior to discharge. These data may then be related to incidence of complications,

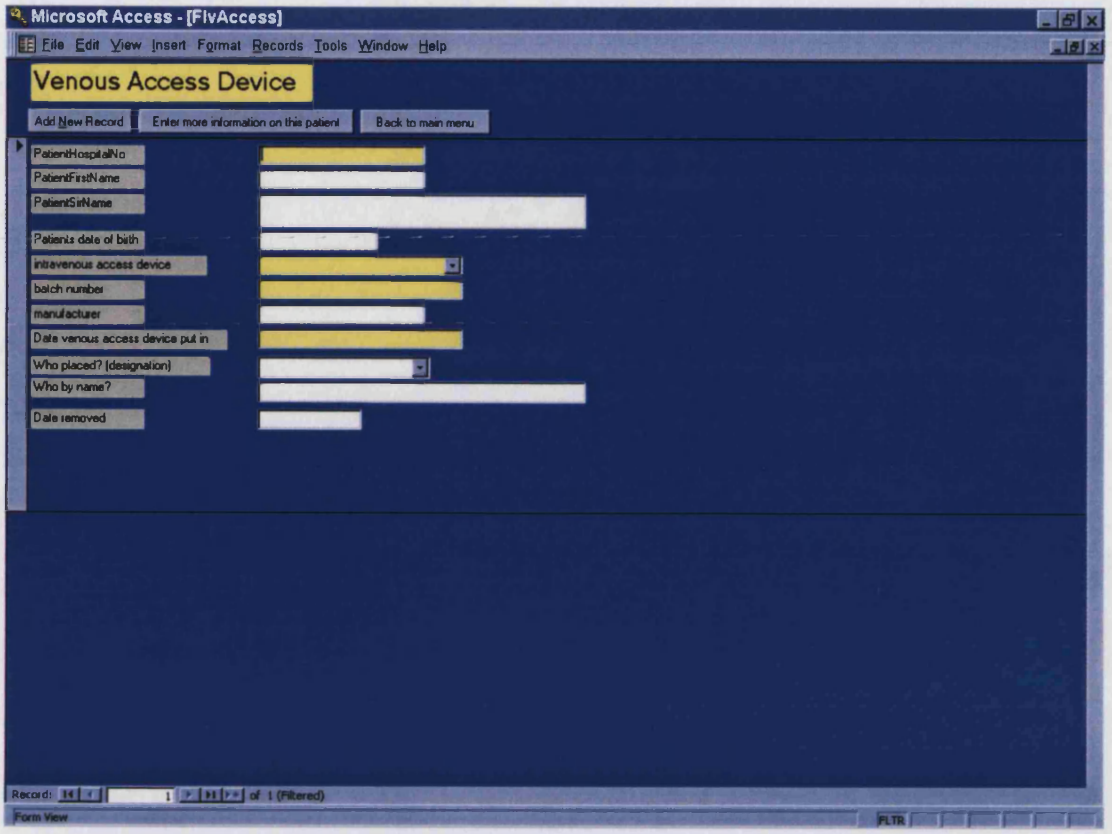
further patient/carer training requirements or readmission rates (Working Example 3, Appendix 26).

4.2.10.5 Venous Access Device

The next form records information regarding the intravenous access device(s) used (Figure 4.14). Including information in the database, such as diagnosis, intravenous access device, type of drug therapy and pump used is important in ensuring that like is compared with like. The incidence of replacement of intravenous access devices in patients receiving their infusion through a peripheral cannula is not comparable with that of those patients receiving their infusion through a central line. The data collected in this form might be used to identify which staff groups have lower incidence of catheter related complications associated with catheter that they have placed or may identify a problem with the technique of a particular member of staff. There have been papers published which suggest that members of staff with a dedicated role in placing intravenous access devices may have better outcome than hospital doctors due to improved technique [344, 345]. From data collected on this form the numbers of days a catheter remained patent can be calculated.

The number of catheter days for a patient can also be calculated from this form and used as a denominator for comparisons of line infection rates etc. This is calculated using the DateDiff function which counts the number of days between the "date venous access device put in" and the "date removed". See working example 4, Appendix 26.

Figure 4.14, Venous Access Device

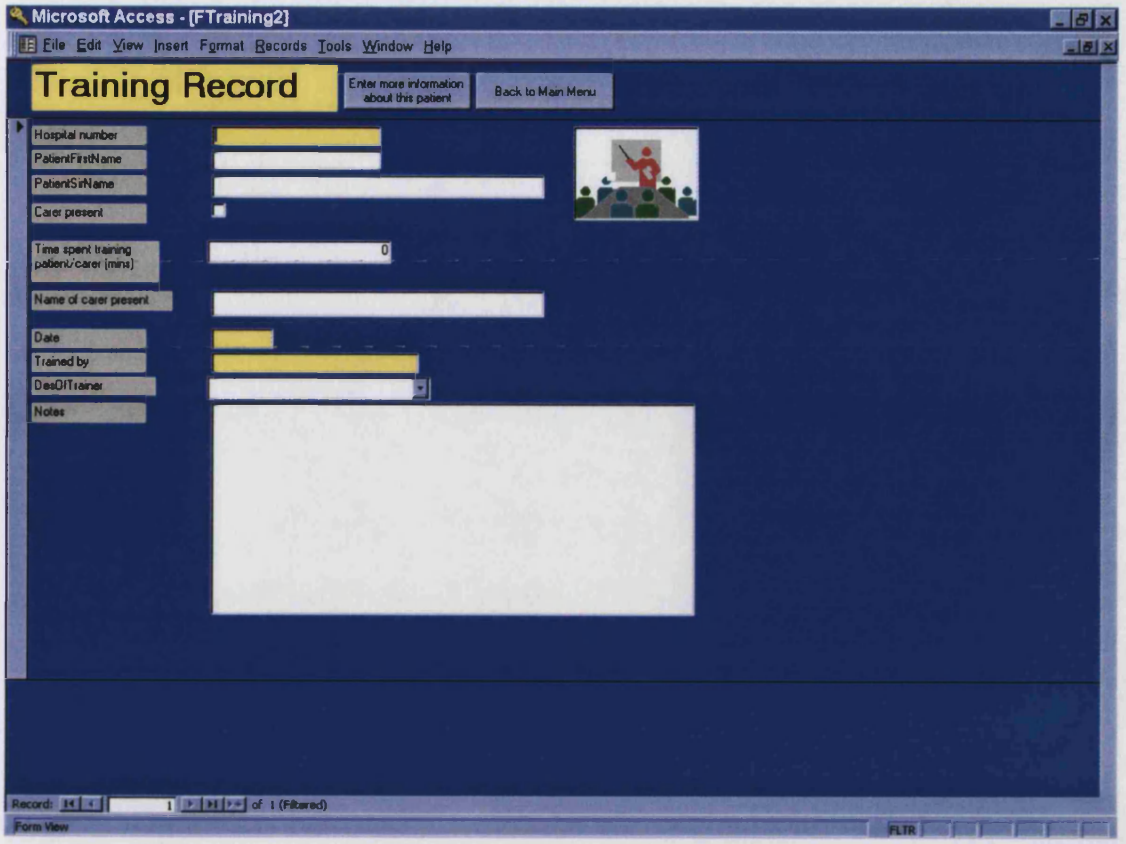


4.2.10.6 Training Record

The Training Record Form (Figure 4.15) allows information to be obtained on the number of training episodes required by patients on particular therapies and the time spent by various members of staff on training. An average can be calculated and used to estimate cost of this part of the service in a managed care situation when tendering for contracts. This serves as a record of particular problems a patient may have encountered in learning to administer their own therapy or look after their line and can be used by healthcare professionals to ascertain where the patient has previously experienced difficulties when they are advising the patient by telephone, in the hospital or on a home visit.

The Training Record also records whether the carer was present at training sessions and who taught the patient that particular technique. Again this could be used to identify staff training needs and learn from best practice. (See working Example 4).

Figure 4.15, Training Record



4.2.10.7 Prescription Record

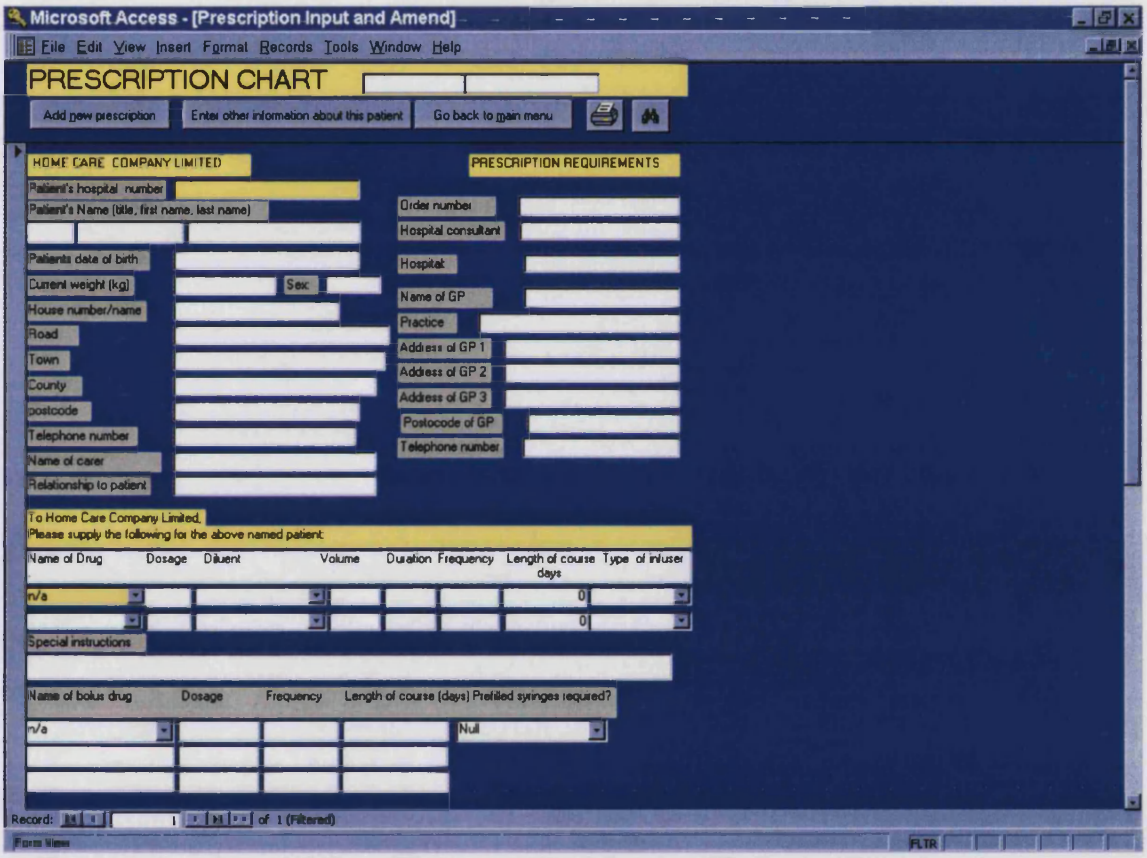
The prescription record (Figure 4.16) was based upon a prescription used by one provider of home infusions (Appendix 27) and was designed to look exactly the same to allow ease of data entry. This meant that the form had, in effect, been piloted and included all of the necessary information. The prescription could be completed on the database, printed off and signed by the doctor to act as the legal prescription, or signed order for the drug. This is why a print button has been incorporated into this form (Working Example 5, Appendix 26).

The prescription allows queries to be performed (records searched, grouped and counted) by drug therapy, start date, prescribing doctor, type of infusion device, intravenous access device and length of course.

Length of course can also be used as a basis to calculate number of infusion days for reports and performance indicators. If the infusion is stopped early for any reason the length of course on the prescription is overridden by the "number of

days therapy if infusion stopped early" field from the Clinical Evaluation form (Figure 4.17). It is important to know the number of infusion days or catheter days. For example one line infection in a patient receiving a home infusion for 7 days is not the same as one line infection in a patient receiving a home infusion for 100 days.

Figure 4.16, Prescription Record



*NB See copy of database on CD (Appendix 26), to scroll down to bottom of page and to see drop-down lists.

4.2.10.8 Clinical Evaluation Form

This form was designed from one already being used by another home care company. It is used to record details of the patients' visits to hospital or a visit made to the patient in their home. It records patient observation which could be plotted in a graph within the database to show trends such as weight gain in a TPN patient. When this form was piloted in a cancer centre it was commented that it would be useful if the database was able to calculate body surface area

from height and weight so this was incorporated. The body surface area is calculated from the patient's height and weight using the Du Bois and Du Bois formula ($S = W^{0.425} \times H^{0.725} \times 71.84$; where S = body surface area cm^2; W = weight in kg; H = height in cm) reference.

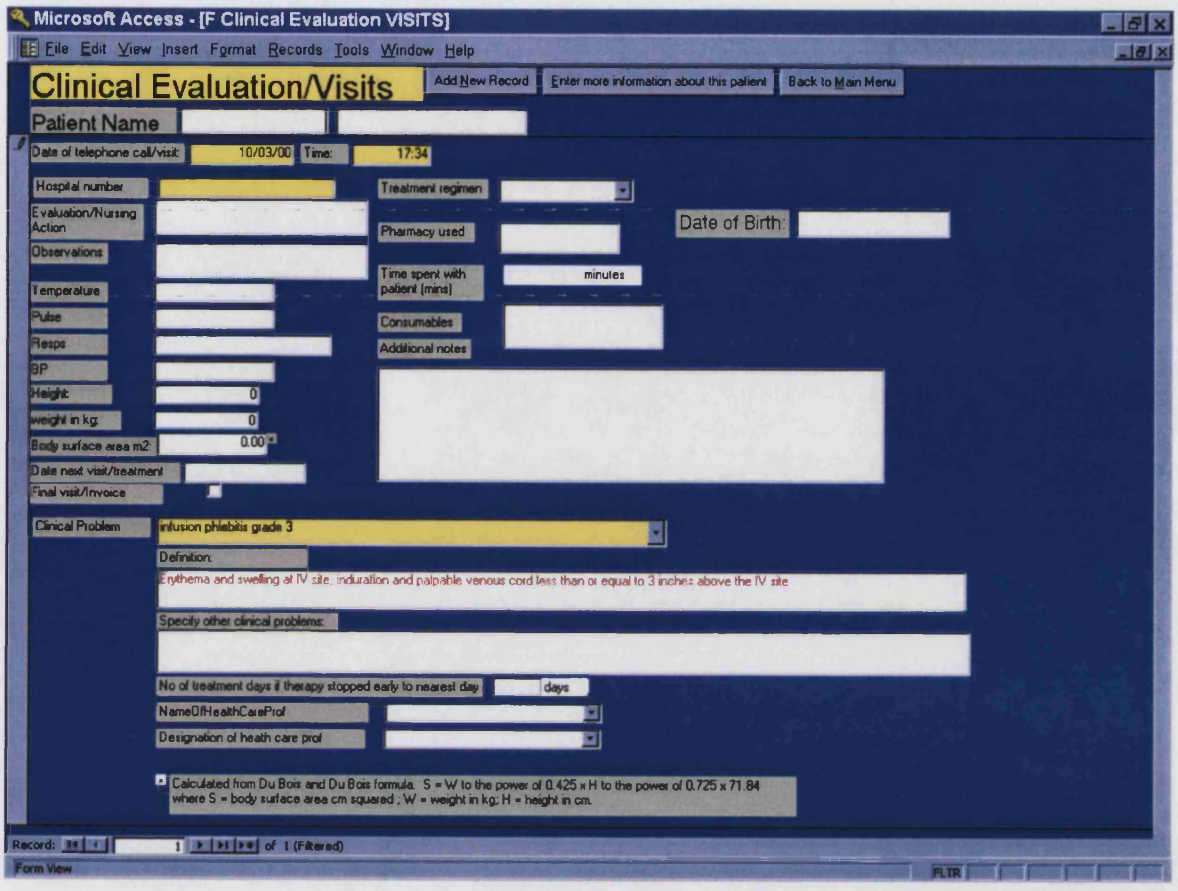
Time spent with the patient was important for commercial billing purposes but also in predicting costs for contracts and for reducing unnecessary patient visits. Number of unplanned visits made outside office hours can be calculated from clinical data input onto this form. It may also be used to monitor the effect of changes in practice put in place to minimise out of hours visits. The clinical problem section was used to record problems in medical terminology rather than the way the patient explained the problem as is recorded in incoming information. This data was used to calculate some of the outcomes which have been more commonly monitored in the Unites States e.g. incidence of line infection.

It was decided that adverse drug reaction classification should be recorded separately in future because it was sometimes not known whether a problem was related to the drug or not. During the pilot a category of "suspected line complication" was included as staff commented that it was difficult always to know whether a problem was related to the line or not. This could be categorised under adverse drug reaction as a Type D-delivery caused by the method of administration.

This form was also used to capture data on unplanned stopping of infusion, unplanned or extra visits to the hospital or to the patient in their home and hospital inpatient admissions.

The length of therapy if treatment stopped early is important as it can be used to recalculate the number of infusion days, rather than using the originally intended length of course recorded on the prescription form. (See Working Example 1, Appendix 26).

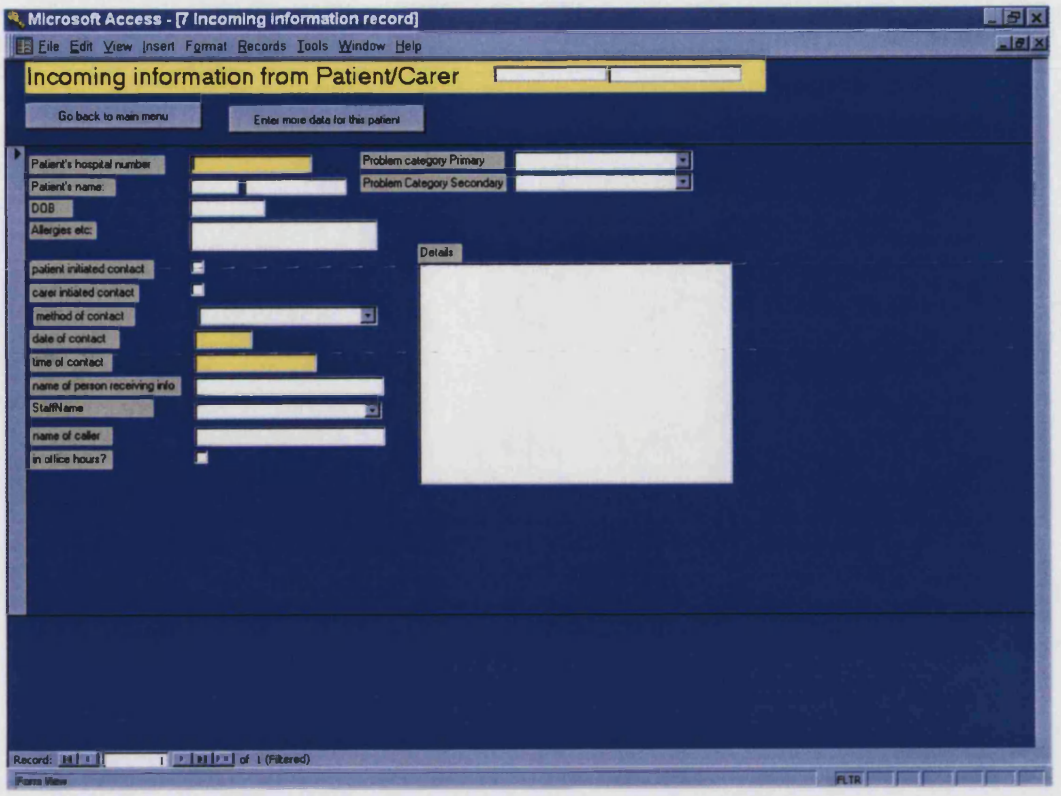
Figure 4.17, Clinical Evaluation



4.2.10.9 Incoming Information (Patient/Carer Contacts)

Patient or carer contact was thought to be important to record. A high incidence of patient contact may reflect an approachable, friendly staff rather than a high number of problems; this highlights the care needed in interpreting the data. Recording details of the subject of patient calls may help to identify information required by patients before discharge or help in development of the training programme. The categories used for incoming problems are shown in Table 4.4.

Figure 4.18, Incoming Information



A primary and secondary problem category were included as a patient may, for example, be experiencing pain caused by a line problem or may be querying quantity of supplies because of a delivery problem. (See working Example 2, Appendix 26)

Table 4.4, Categories Used to Classify Incoming Information from Patients or Their Carers

Problem ID	Incoming problem category
1	storage
2	drug administration
3	line care
4	feeling unwell
5	pump
6	quantity of supplies
7	delivery
8	ancillary items
9	pain
10	other
11	none

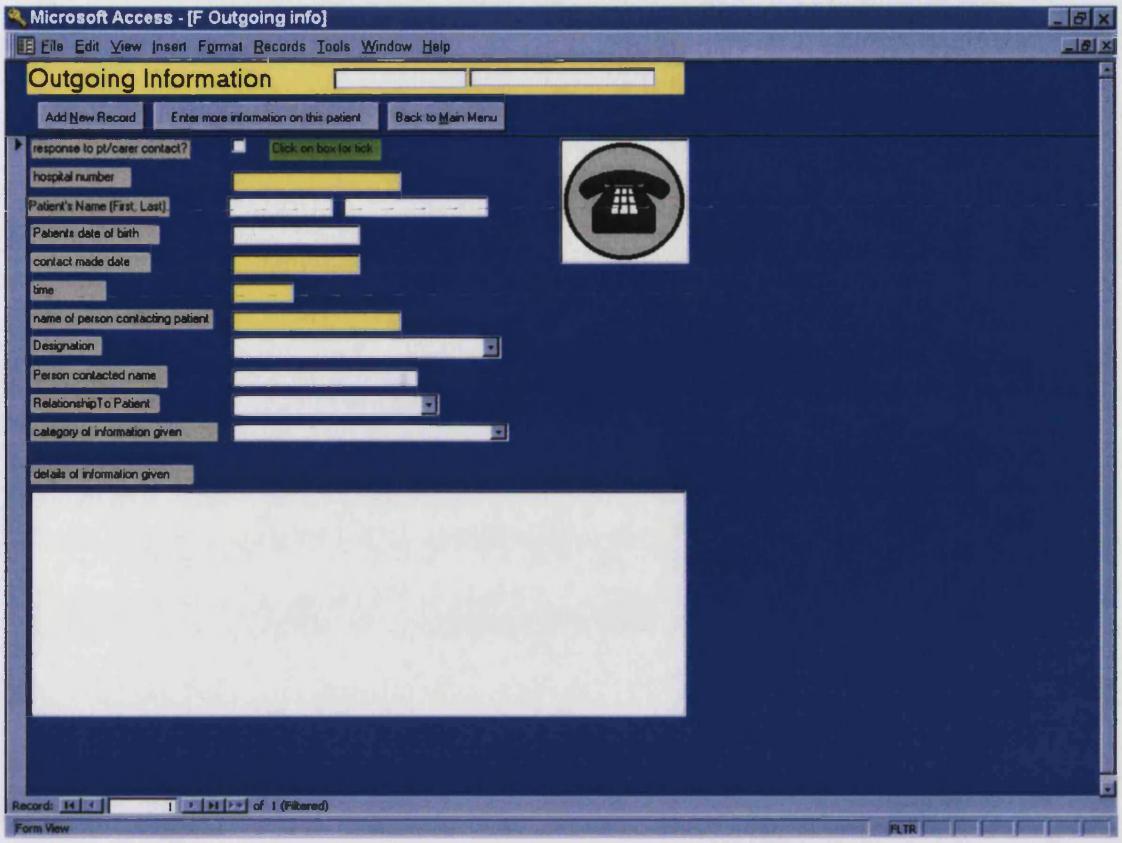
4.2.10.10 Outgoing Information

A record of who gave what advice to the patient when was also considered useful for a co-ordinated approach from the healthcare professionals looking after a patient and also for monitoring the categories of information given Figure 4.19. Again this could help in identifying gaps in training or written information given to the patient and their carer and could identify staff training needs if related to the staff or staff groups responsible for training the patient. Another example of how this information could be used is in relating the frequency of outgoing information regarding pumps to the type of infusion device used from the prescription record. Infusion devices that patients had less problems using could then be chosen if appropriate or extra information on the use of the device could be provided. The categories of outgoing information from the hospital, home care company or primary care professional are shown in Table 4.5

Table 4.5, Categories Used to Classify Incoming Information from Patients or Their Carers

Category ID	Category outgoing info
1	Delivery
2	Advice re Pump
3	Consumables
4	Equipment e.g. fridge
5	Advice re line care
6	Advice re drug administration
7	Other

Figure 4.19, Outgoing Information



4.2.10.11 Other Forms For Data Collection

Two other forms were included which were not piloted in the evaluation these were to record despatch of infusions and quality control Figure 4.20 and

Figure 4.21. It has already been noted that information regarding home infusions is stored in disparate places and it was found when piloting the database as a data collection method that the information regarding quality control of the infusions and despatch is not readily available by the same people who have access to clinical information.

The idea of the database is that it could be networked so that information from all staff caring for home infusion patients can be collated including that from different departments of a hospital such as the ward, outpatients, pharmacy, outreach nurses, commercial providers and primary care. Levels of security could be incorporated to give delivery staff and others access to information that would be useful to them and allow them to input certain information.

Figure 4.20, Despatch Check Form

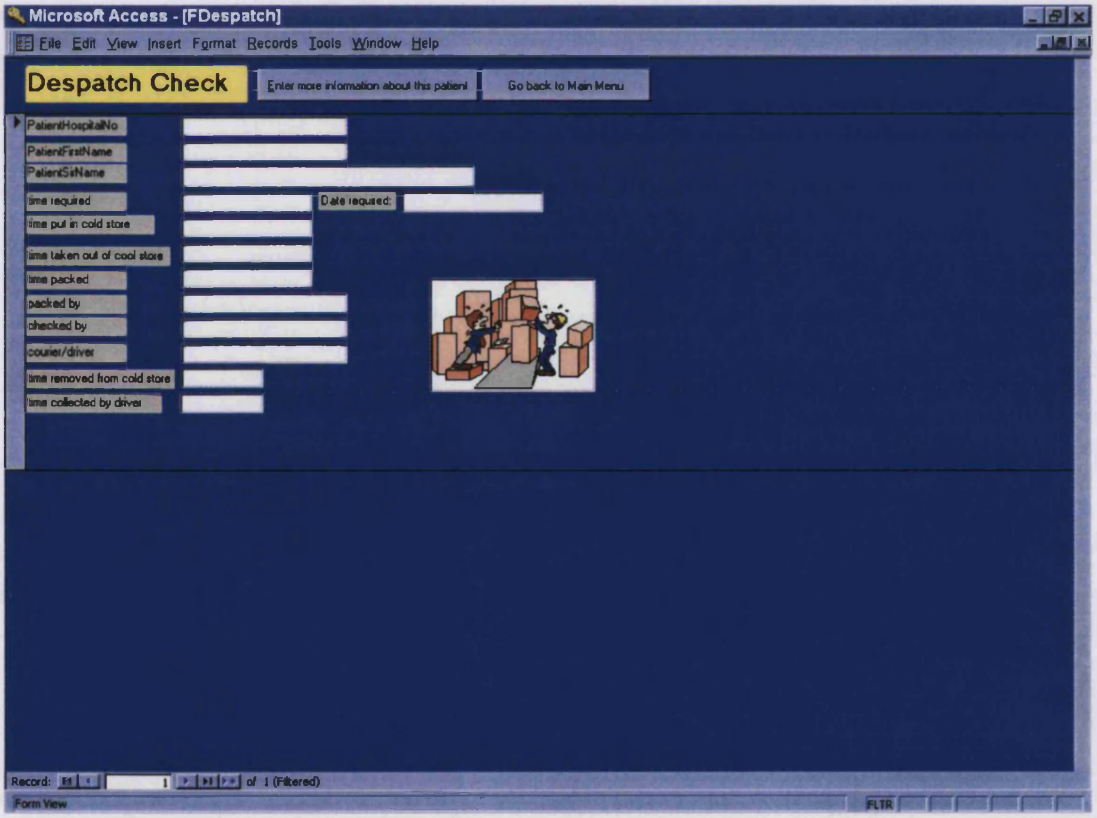
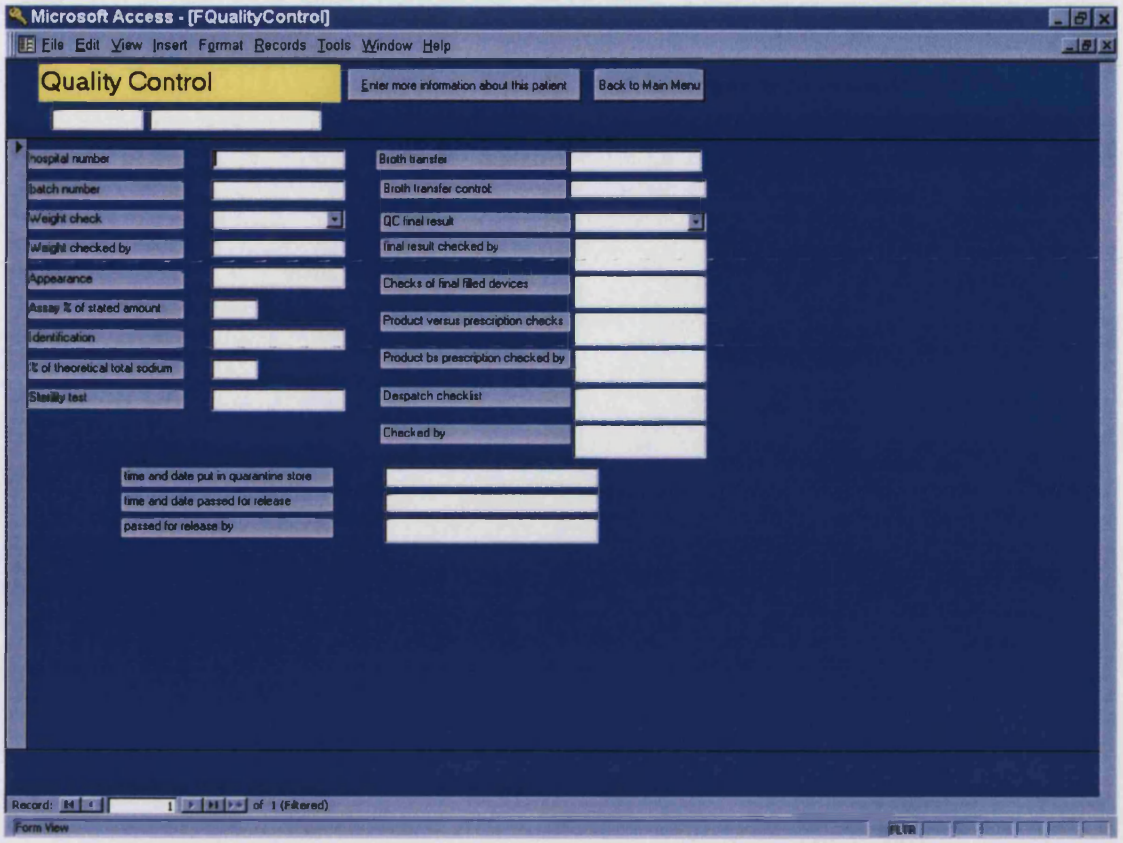


Figure 4.21, Quality Control of Infusion Form



4.2.11 Design a Tool to Analyse the Data

The data was analysed using queries and reports incorporated into the Access® software. It was necessary to manipulate the data for the reports. In order that data is comparable between centres an attempt was made to calculate the incidence of the measures used such as complications of catheter occlusion or blood stream infection. Frequency of complication per number of catheter days was calculated so that centres can compare their rate of complications per number of days the patient had a catheter *in situ*. Some studies compare rates of an incident per number of infusion days, however, all the time the patient has a catheter *in-situ* even if it is not being used for an infusion there is the potential for drug delivery related adverse drug reactions. It is possible to calculate incidence both by number of infusion days and by number of catheter days from the information stored in the database. Incidence of clinical problems has been calculated per 100 catheter days in the example reports given.

A problem arises that one patient may in a very small number of cases have more than one catheter *in-situ* at the same time. If a patient has two catheters *in situ* for 7 days should this count as 7 catheter days or 14? It was decided after some discussion with staff looking after home infusion patients that the risk of complications from each line was additive and therefore the number of days should in the above case be recorded as 14 rather than 7. The queries were set up to incorporate this so that in the above example 14 catheter days would be used in calculating the incidence for the report.

Select queries were used to select the required information and calculated fields were incorporated to calculate incidence. In order to calculate the number of catheter days select, make table, update, append and delete queries were used. Functions such as "IIf"and "DateDiff" were used to calculate the number of infusion days and number of catheter days.

Number of infusion days can be calculated by taking the largest length of infusion from infusion 1 and infusion 2 and returning this unless "number of days treatment if infusion stopped early to the nearest day" was completed on the "clinical evaluation/visit" form in which case this should be returned as the value for number of infusion days.

A problem was encountered whereby one patient may have many prescriptions and those many prescriptions may be associated with many records of "clinical evaluation/visits" (a many to many relationship). If the infusion stopped early section was filled in on the "clinical evaluation" form the computer had to be told which prescription this referred to so that the correct value was overridden. Clinical evaluations may also occur outside of the time that the patient is actually receiving the infusion. It has been assumed that in this case the infusion stopped early field would not contain a number of days because there would be no ongoing infusion to stop early. The start date of the infusion plus the number of infusion days was used as a time period over which the patient was receiving this infusion. The computer was programmed to search the prescription records to find the appropriate prescription using a complex set of greater than and less than

commands for date and time.

It can be seen from the above that the number of infusion days is reliant on the prescription so that every time a patient has a prescription this needs to be entered onto the database. If, for example, a patient is receiving a 14 day course of an antibiotic infusion and two prescriptions each of one week in duration are written both must be entered onto the database and the start date of the second must be 8 days after the start date of the first, it cannot be the original start date of the course.

One idea to overcome these sorts of problems was to incorporate the concept of a treatment episode which for chemotherapy or antibiotic infusions would seem logical. It was very difficult to define an episode in terms of fields input so that the computer was able to identify one episode from another. Patients receiving TPN or desferrioxamine infusions do not fit these categories. Is a break in the infusion of one or even two days the end of an episode? It would be for an antibiotic infusion but what happens when a TPN patient has three bags a week?

The reports incorporated as examples later in this chapter (4.2.13) start by asking the operator the time period over which they wish to report. If the start date chosen is after the "date catheter put in" date then the chosen start date is returned and similarly if the "date catheter removed" date is after the end date the end date is returned. For catheters that have been put in but not taken out today's date is returned as date removed for the purpose of the calculation. It is therefore very important to make sure that data input is up-to-date before running reports. As with any database the output is only as good as the quality of the data input.

By using the number of catheter days rather than the number of infusion days the incidence of some complications may appear to be lower than those reported in some of the literature. This makes it difficult to compare like with like, hence the need for clear definitions. Williams *et al* [28] give an incidence of catheter related sepsis per number of patient months receiving TPN, it appears that this has been calculated using duration of catheter placement in months but they do not define a month making it difficult to compare this to other data which is

given in terms of days, although this can be extrapolated to a year and divided by 365 to give an estimation. If all benchmarking partners are using the same tool then calculations will be made from the same data ensuring that data is manipulated in the same way, and assuming integrity of the data input, comparisons will be more accurate although this will not account for external factors such as case-mix already discussed.

Comparing incidence such as a complication per 100 catheter days can be a problem because in a centre whose number of catheter days is low one incidence of a complication could skew the incidence significantly when comparing it to data of another centre with far more patient catheter days. Patients who did not have a catheter left *in situ* (i.e. they had a new catheter placed each time they had an infusion administered) were excluded from the analysis in the reports shown in the database.

A further adaptation required was discovered on piloting the database. This was the need to include a field asking whether this was the first time that the clinical problem had been recorded. Initially on the "Clinical Evaluation/Visits" form the nursing staff were recording the same problem on each occasion that they saw the patient so that a centre who saw the patients with clinical problems regularly appeared to have a very high incidence of problems but in fact they may well have been just providing better care or more support for their patients.

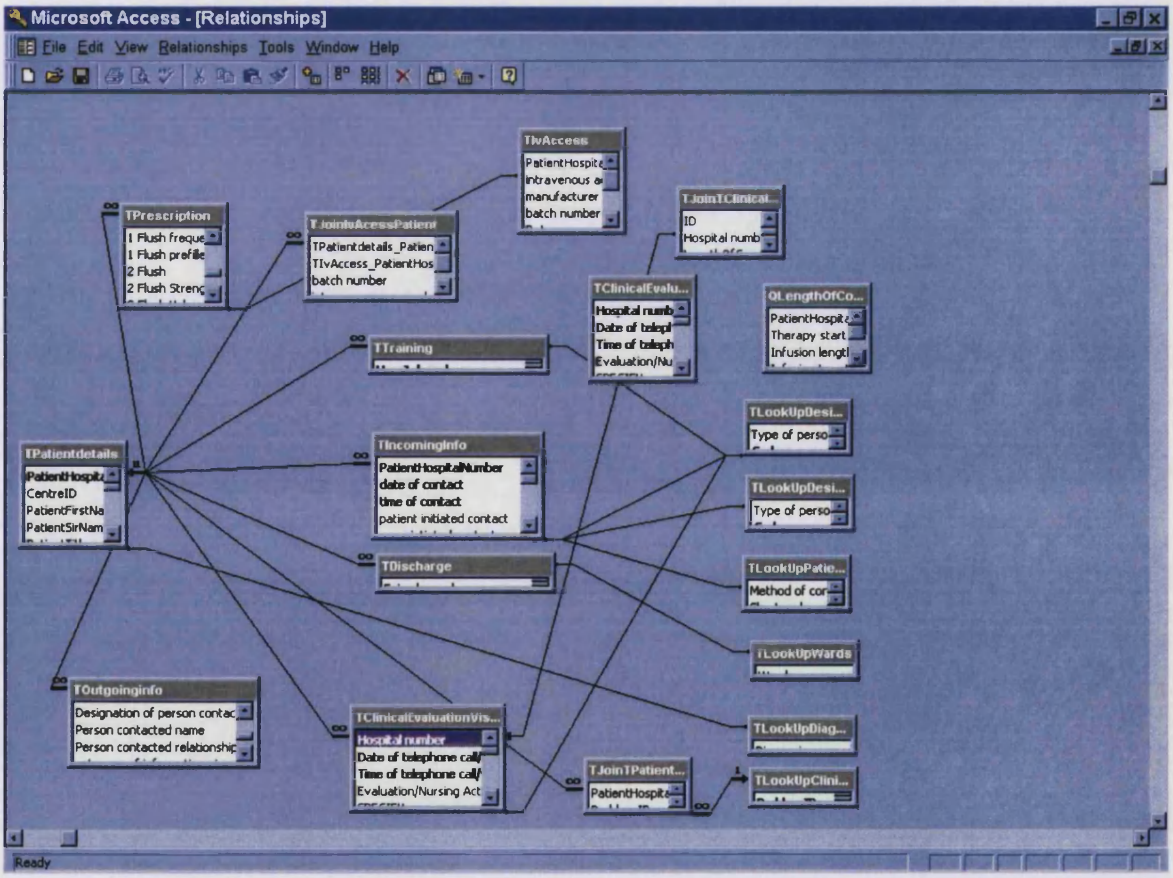
4.2.12 Validation of the tool.

It was almost impossible to develop the benchmarking tool without having any real data to put into it, as it was only then that many of the problems of logic in the relational database were highlighted. It was difficult to determine the relationships between each of the tables. The relationships formed are complex and are shown in Figure 4.22. The mapping of the processes was used to develop relationships in a database in a logical manner. A difficulty arose where circular relationships were the only logical way to relate tables but this causes problems for the database in that when running queries it does not know which way to go around the relationship.

The piloting, feedback and subsequent redesign of the database was almost a continuous, circular process and has therefore been discussed in the development of the tool. Two home infusion centres contributed data, one was a cancer unit of a NHS Trust and the other was a commercial home care provider. The database was piloted in these two different settings to ensure that it would function successfully in both models of providing home infusions.

As the reports were designed each report was validated by calculating the expected output from the raw data held in the tables of the database. Further validation of the database would be required as further data is input and more reports set up.

Figure 4.22, Relationships



The number of patients entered into the database during piloting was small and it

is probable that further problems may emerge as more data is entered. It takes many months to build up a picture of one real patient and even longer to come across all the many scenarios which may emerge. The small amount of data incorporated here is one of the main limitations of this work.

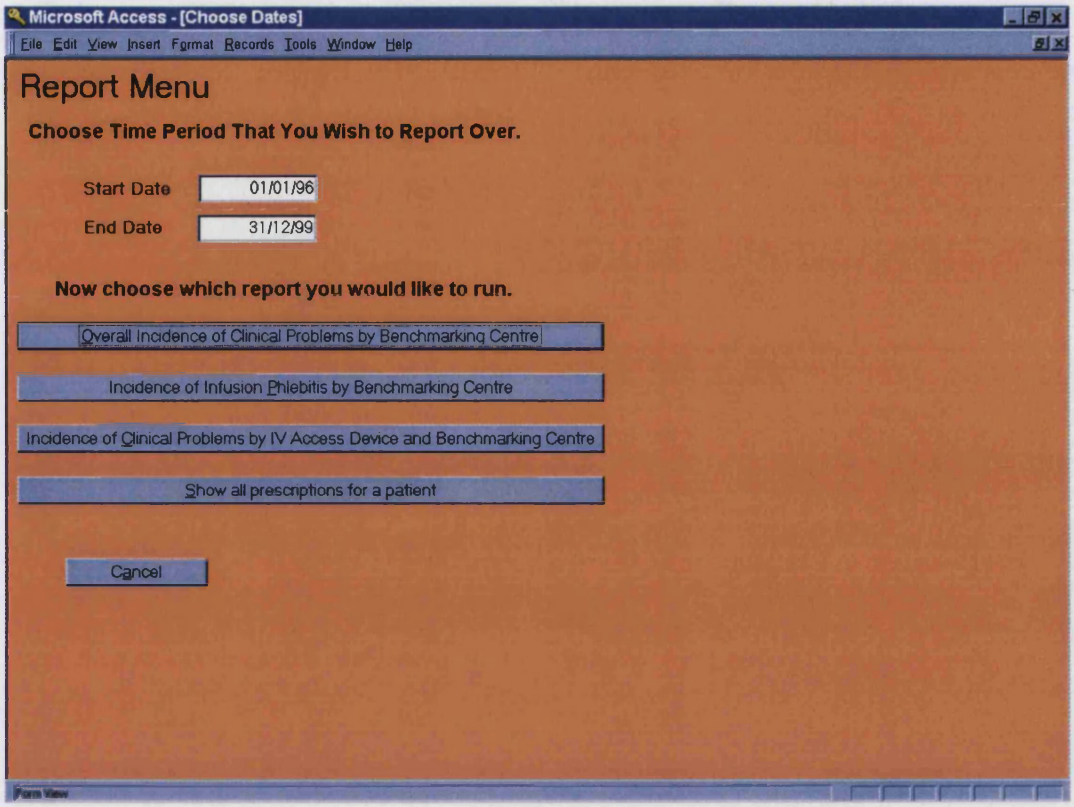
It is often computer programmers who develop these sorts of programmes and a major problem with these is the programme is designed around the software rather than the software being designed around it's application. This is purely because the computer programmer generally has a far greater understanding of the software than they have its application. This programme has been designed around the provision of home infusions and some of the programming now needs to be improved. Further development was limited by the researcher's ability to programme more complex aspects of the database.

A manual explaining the importance of completing fields and how the computer has been programmed to calculate certain outcomes would be the next step after the design of the software has been finalised by further testing. A small help section could also assist users to overcome the majority of problems they might encounter.

4.2.13 Reports

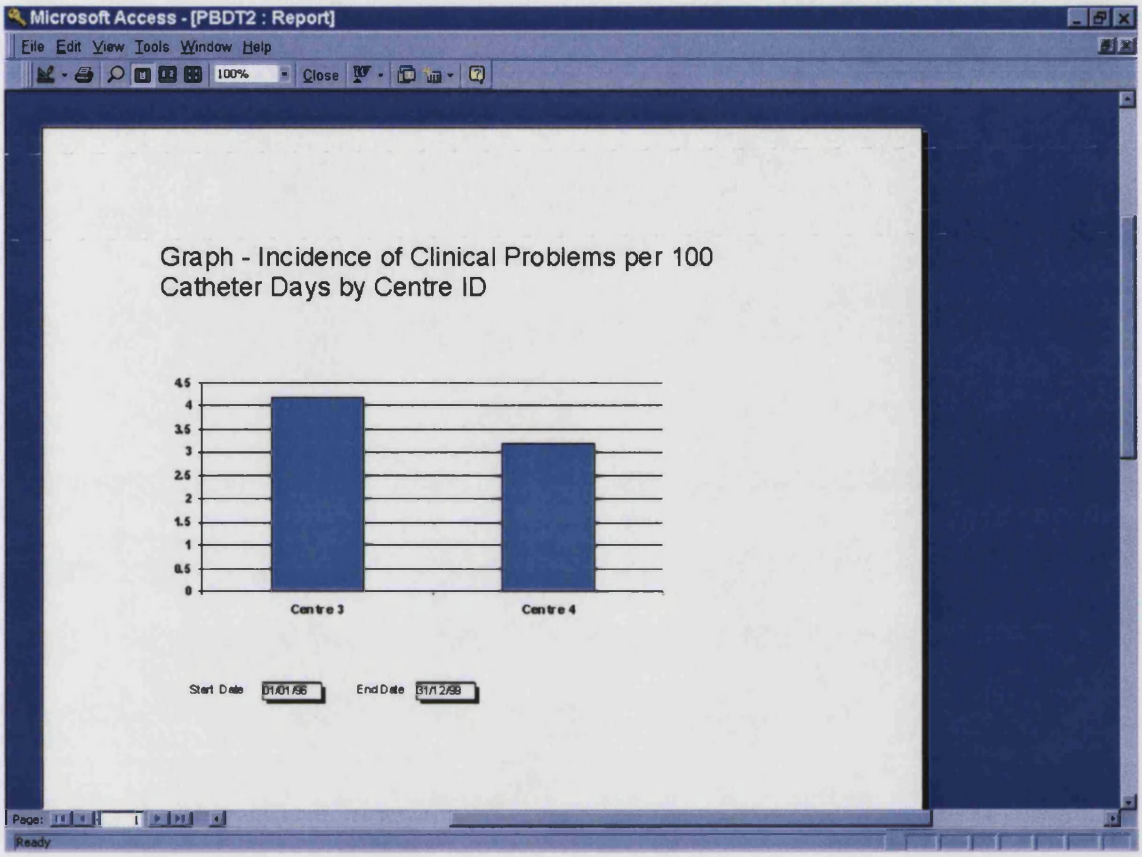
Reports are accessed via the main menu "reports" button, which is linked to the report menu form (Figure 4.10). This gives the operator the opportunity to choose a time period over which they want the report run. The finish date defaults to today's date but this may be overridden. Four example reports have been programmed in. The data used in these reports is fictional, as much more data would have to be input before an incident of some of the rarer events would occur.

Figure 4.23, Report Menu



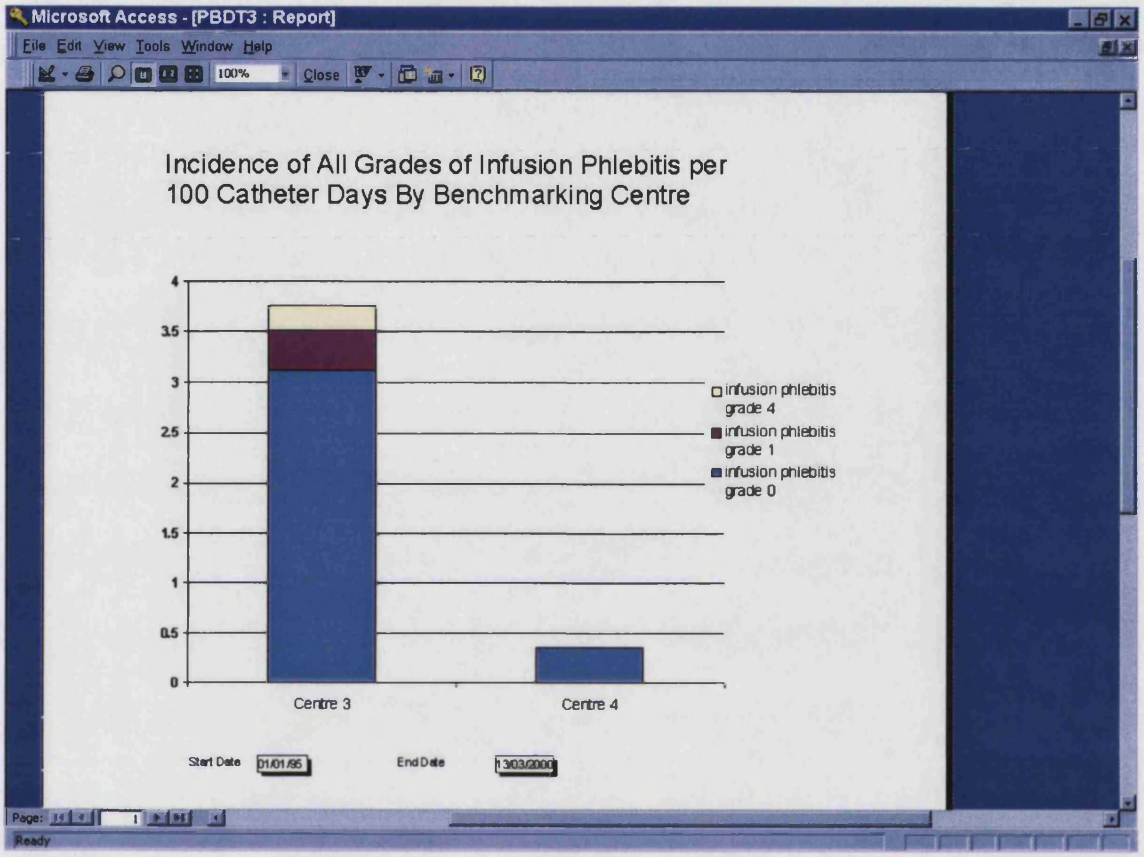
The first is an empirical report showing overall incidence of clinical problems by benchmarking centre and is presented as a graph (Figure 4.24) (see Working Example 6, Appendix 26).

Figure 4.24, Report 1, Incidence of Clinical Problems per 100 Catheter Days by Benchmarking Centre



This obviously needs to be broken down further into, for instance, the report that shows incidence of infusion phlebitis by grade and benchmarking centre (Figure 4.25) which gives a much better comparison (providing that the same definitions have been used to grade infusion phlebitis). (See Working Example 7, Appendix 26).

Figure 4.25, Report 2, Incidence of All Grades of Infusion Phlebitis per 100 Catheter Days by Benchmarking Centre

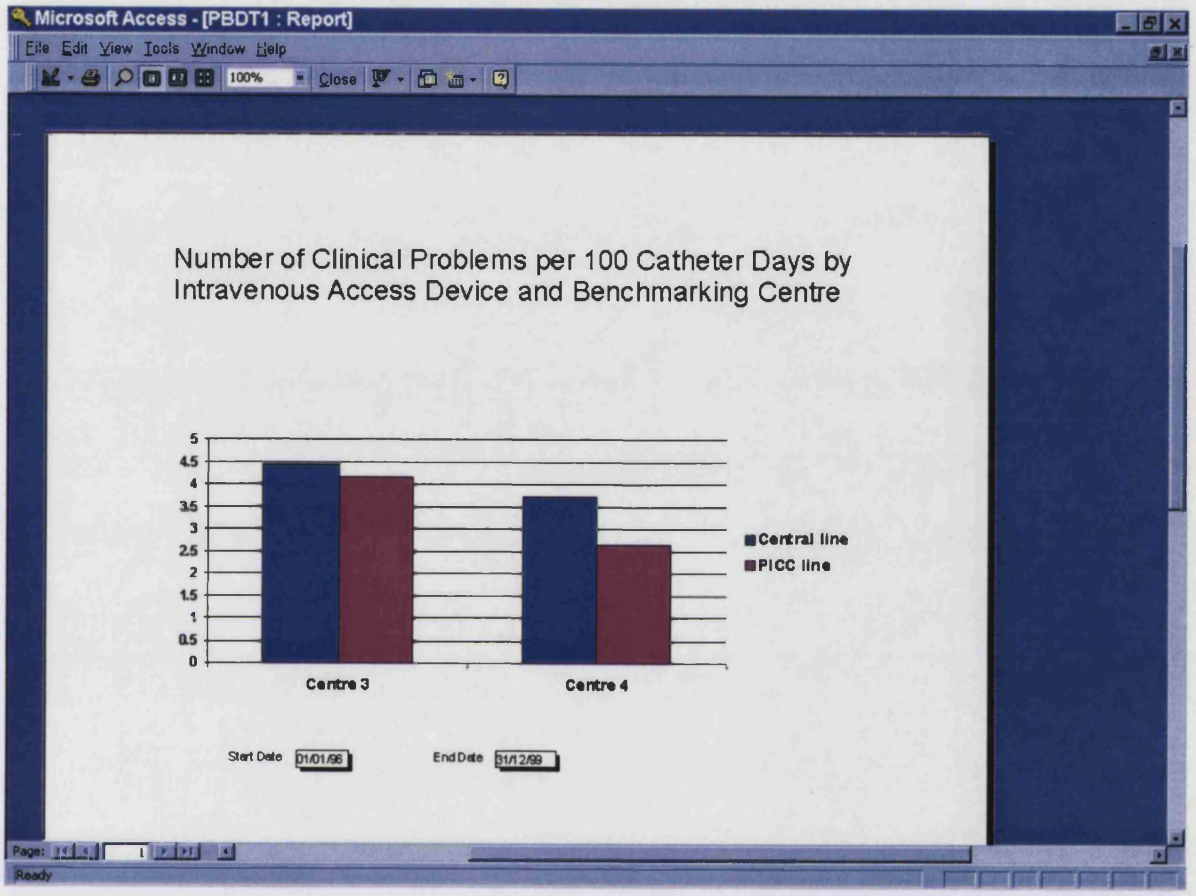


It may not however be useful to compare incidence of clinical problems without specifying which type of intravenous access device was used as incidence of complications is affected by this [339]. The next example report (Figure 4.26) shows incidence of clinical problems reported by intravenous access device (See Working Example 8, Appendix 26).

The reports included in the database are just a very small number of examples of reports that can be programmed into the database. The combination of these types of reports can be used to highlight differences in benchmarking centres and to identify best practice. Each separately stored field can be queried and shown against any other field held in the database so that there are almost an infinite number of hypotheses that these data can be used to test. Once the data is stored in this way it then becomes possible to use it when new questions arise. It should be noted that all of this information is already collected but because of the way it

is recorded and stored it is not currently used to improve patient outcomes and the quality of care they can expect to receive.

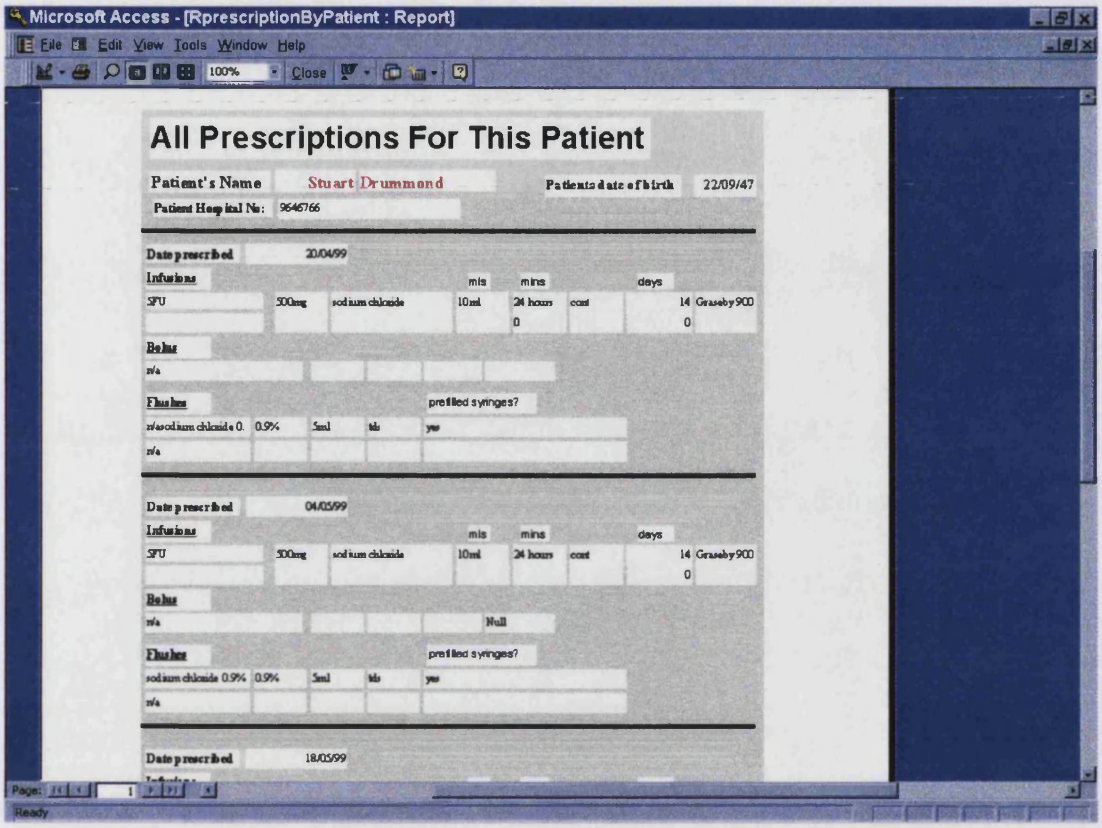
Figure 4.26, Report 3, Number of Clinical Problems Per 100 Catheter Days By Intravenous Access Device and Benchmarking Centre



The database also makes it very easy to access a history of patient details; an example of this is given which lists a summary of all of the prescriptions that have been written for a particular patient (Figure 4.27). (See Working Example 9). The same could be done to print out a summary of communication with the patient or clinical problems before a visit to that patient or before an outpatient appointment. Clinical monitoring could be shown as trend graphs for measures such as blood pressure, temperature and weight and different reports could be specific to measure outcomes of different patient groups such as respiratory function test for cystic fibrosis patients or pain scores for patients receiving infusions for pain relief. It is possible to separate patients by diagnosis but

would require far higher numbers of patients to be input into the database to achieve meaningful comparisons.

Figure 4.27, Show All Prescriptions For One Patient



The database would require further piloting and more advanced programming if it were to be made available for general use. One centre that piloted an early version of the database continued to input data for their own benefit after the period of the pilot so that they had easy access to their patient information as a central resource.

The situation that has occurred in the United States is that providers provide information to a commercial benchmarking centre who collate it and compare it to other similar providers, matched for case mix, size of population and size of company. Payers require this information when the providers tender for contracts.

4.2.14 Discussion and Future Work

The limitations of this database as a tool for benchmarking home infusion providers have been discussed throughout this chapter. This work has shown that it is possible to develop a benchmarking tool which achieves the purpose outlined in 4.2.3. A patient centred database has been designed that can be used by providers of home infusions to compare outcomes and performance indicators, to identify trends and problem areas, to monitor the effect of changes to the service, improve patient education and to improve communication between health care professionals. Data collected and manipulated appropriately can then be used to aid purchasers in identifying cost effective care packages, setting service specifications, monitoring of contracts against specifications, setting and achieving clinical governance targets and ensuring that home infusion therapy provides acceptable outcomes.

This work represents the very first stage in development of such a tool. It is not a fully functioning tool ready for use. In order to take this further the skills of a computer programmer would have to be employed. There are obvious limitations of the programming and further technical work is required to develop a fully comprehensive software tool. Similarly the development of the tool would require far more real patient data to be entered and the outputs validated to ensure that the database functioned effectively. Refinements in the relational nature of the database and the way data is stored, manipulated and entered are needed. It is envisaged that a software package would have to be, probably commercially, developed to bring it to a standard required for day to day use. Further discussion of this is outside the scope of this work.

This work has shown the necessity for such a tool to be developed using a constant cycle of design, piloting, feedback and validation and this methodology would need to be employed in further refinement of the tool. The clinical definitions, performance indicators and benchmarks would need validation to ensure that like is being compared with like and also that appropriate conclusions were being drawn from the data. To validate the use of the tool as a whole it would have to be shown ultimately to improve patient outcomes. This would

involve ensuring that the tool was used to challenge current practice and constantly learn from best practice, implementing process adaptations to achieve better outcomes.

Feedback from clinicians was positive during the piloting but to gain full benefit from the benchmarking tool involves a complete change in the way clinicians work. Training of staff would be a very important part of implementing benchmarking of home infusion services. It is not only important that the data is input in an accurate, comprehensive and timely way but also that once stored in the database the information is used to stimulate critical appraisal of the processes employed and to adapt best practice to improve patient outcomes.

Achieving buy-in from the staff is very important. They must see that this is a way to improve the quality of care that they deliver to patients. In the USA the motivation for home infusion providers to carry out benchmarking is that insurers and payers require this information before they will purchase care and often will require that the providers outcomes fall in the upper end of the range. In the UK, clinical governance initiatives supported by the Commission for Health Improvement (which aims to identify and share good practice) may provide the motivation for home infusion providers to benchmark services. The Department of Health has, in recent years, tried to encourage learning from best practice with the introduction of their beacon scheme [346]. There is limited competition in the home infusion market in the UK but in the commercial company survey one commercial provider of home infusions specified that they wished to benchmark their service against that of others to demonstrate the high quality of the service they provide which will help them to make sales.

Using the experience of other industries in employing benchmarking techniques it would be necessary for some sort of discussion forum to be established for sharing ideas, comparing benchmarks, developing better and more meaningful benchmarks and learning from best practice.

There remains much work to be done in developing valid indicators of performance to use as benchmarks. In the USA, where benchmarking of home

infusion providers is well established the indicators are not standard despite attempts by the JCAHO to develop a set of indicators which underwent alpha testing in 1992 (4.1.4.1.1). Collecting data and storing it together in discreet fields in the database facilitates the development of better more useful benchmarks.

In order for a benchmarking tool such as this to achieve maximal benefit to patient care it would have to be networked so that all NHS health professionals and commercial providers have access to all the information they need to provide best quality care for the patient. The development of the NHS net is bringing us closer to the aim of having all information stored about a patient in the NHS being held together and being accessible to those who require it to benefit patient care. It is intended that it will eventually be used in empirical benchmarking of health care organisations. The current situation remains that patient information is stored around the organisations and departments providing the care and not around the patient. It is hoped that eventually a tool such as has been developed here would be compatible with a patient centred database where all the health information regarding that patient is stored. First steps towards linking general practices and community pharmacies with electronic prescribing were announced in the NHS Plan [5] and pilots will start this year with the aim of making this a reality by 2004.

A first step would be for those involved in home infusions to monitor defined patient outcomes and establish the processes that lead to those outcomes. Sharing of information will lead to identification of good practice and facilitate improved patient care by learning.

With the formation of PCTs it seems that unless commissioning of home infusions is done in a collaborative way the small numbers of patients will mean that there is a risk that service specifications will not be set, outcomes of individual patients are unlikely to be monitored and the quality of care received by patients receiving hi-tech health care at home is unlikely to improve.

5 Overall Discussion

This chapter draws together the main discussion points from Chapters 2, 3 and 4 to make overall conclusions and recommendations regarding the management of hi-tech health care in the community setting. The work has highlighted both opportunities and major barriers to the provision of high quality care, with ever more hi-tech therapies closer to patients' homes. This is in line with the government white paper "Our Healthier Nation" [3] and the NHS Plan [5].

5.1 Sharing the care of patients on hi-tech/specialist drug therapies

AIM 1

To establish the current situation in England regarding the implementation of shared care arrangements under EL(91)127 [19] and subsequently under EL(94)72 [21] and to identify models which had been successful or otherwise.

AIM 2

To evaluate and critically analyze one example of an initiative intended to implement and facilitate shared care between primary and secondary care practitioners in South and West Devon.

Shared care guidelines have become widely adopted in various forms throughout England but the numbers in each Health Authority area were small at the time of this study (average of six per Health Authority area in 1996/7), section 2.2.5.1.2. They were generally found to cover a limited range of therapies where there has been contention about where prescribing responsibility should lie, (Section 2.2.5.1.2)

Many of the available shared care guidelines have been produced on the subject of higher cost therapies and Health Authorities have often facilitated their introduction (2.2.5.1.3). It is likely that gaining agreement about where prescribing responsibility should lie, with the backing of the Health Authority, through a shared care agreement, has ensured that resource for prescribing these high cost therapies is vired to the appropriate budget, i.e. ensuring the money follows the patient. An example of this would be erythropoietin prescribing

(Appendix 5). The Health Authority survey showed that in areas where GPs have agreed to prescribe under a shared care agreement, funding to cover the cost has been allocated via mechanisms, such as high cost drug contingency reserves, into their budgets. Conversely in areas where there has been agreement that prescribing should remain in secondary care money already spent on prescribing erythropoietin in primary care has been top-sliced from primary care prescribing budgets and vired back to secondary care (Appendix 5 and Section 2.2.6.1.5.1).

Although this may be a motivating factor in producing shared care guidelines it is interesting that the survey of a sample of GPs showed that when GPs were asked what they would most like guidelines developed for it was not the high cost drugs that they most frequently requested (Appendix 10 and section 2.2.6.2.5). The drugs were relatively low cost and those which a GP is unlikely to prescribe for large numbers of patients, such as disease modifying agents used in rheumatoid arthritis, methylphenidate and atypical antipsychotics. It seems from this work that GPs value shared care guidelines for their clinical direction. Drugs such as the DMARDs are potentially very toxic and it may be that GPs like to have guidelines for prescribing and monitoring such therapies because by following the shared care guidance their actions are likely to be more easily defensible if legally challenged. The GPs surveyed were happier to take on prescribing of these drugs when a shared care guideline was available (section 2.2.5.2.4.). This finding supports that of Horne *et al* [347] who found that "... GPs' concerns about lack of knowledge to discharge their clinical responsibility fully in relation to prescribing seemed genuine".

Drugs such as methylphenidate [348], rosiglitazone [349] and donepezil [350] have recently become the subject of NICE guidance. The guidance on methylphenidate [348] gives recommendations as to when it should be prescribed and who should initiate the treatment. It recommends that GPs may share care with a child psychiatrist or paediatrician under a locally produced shared care guideline. It will be interesting to see whether such guidelines in the future will contain less clinical information which will be available as part of the NICE recommendation and focus more on defining the respective responsibilities of GP and specialist. If NICE continues to define suitability for shared care in this way

it is likely that there will be an increase in the number of shared care guidelines available. This will be driven by the fact that compliance with NICE guidance will be audited. Audit may be a condition of commissioning arrangements, it may be part of clinical governance arrangements and the Commission for Health Improvement will be looking for compliance with NICE guidance during it's inspections of both primary and secondary care providers.

The Health Authority and GP surveys showed that respondents perceived that both the shared care guidelines themselves and the process for development of these guidelines have contributed to improving communication between primary and secondary care physicians. However both HAs and GPs commented that hospital specialists still often fail to recognise the ethical and emotional dilemma that GPs face when asked to take on prescribing of hi-tech therapies. They still assume that a GP will take over prescribing hi-tech therapies and tell the patient that this will be the case (Appendices 5 and 11). This then puts GPs in a difficult position. This finding supports that of Mailey *et al* [106, 347] and was recognised by the Royal College of Physicians in their recent Working Party Report: Prescribing of Costly Medicines [22] where it was recommended that prescribers in secondary care take into consideration the anxiety that those in primary care may have about prescribing certain new medicines. It would have been useful to survey the secondary care consultants as well as the GPs in South and West Devon in order to determine the success of the guidelines from their point of view and to ascertain whether the perceived misconceptions of consultants were real. This work is currently being undertaken in South and West Devon by the Shared Care Working Group [351]. The work of Horne *et al* [347] would suggest that the views attributed to hospital doctors by GPs in this survey are reasonably accurate.

During the period of this research most of the guidelines were developed by committees facilitated by Health Authorities. Health Authority, hospital and less frequently, community pharmacists were heavily involved in drawing up, getting agreement on and implementing the guidelines (section 2.2.5.1.3). Membership of the committees was very similar throughout the country. The role of the Health Authority in the reorganisation of the NHS has changed since 1996/7.

Health Authorities have taken on a more strategic role and are responsible for performance management of PCGs and PCTs [5, 352] Health Authorities will shortly be abolished in Wales and there will be fewer of them in England [353].

Since the introduction of PCGs and some PCTs there have been new committees or groups formed often referred to as Drug Interface Groups or joint primary and secondary care Drug and Therapeutics Committees. These link into, or in some instances have replaced, existing Area Prescribing Committees and Drug and Therapeutics Committees. They provide a forum to discuss interface issues around prescribing usually between a secondary care provider and the main PCGs and PCTs associated with them. Representation on the groups is similar to the older Health Authority committees but there may be greater potential for agreement on shared care issues at a more local level. It seems that future commissioning arrangements will specify where prescribing responsibility for certain drugs lies, now that purchasing responsibility sits within primary care. Delegating decisions to a local level has benefits but may also lead to duplication of effort in the development of shared care guidelines and potential problems when a GP practice refers patients to a number of secondary care providers each of whom have different shared care agreements.

The "traffic light" system mentioned by some Health Authorities in the survey (Appendix 5) has become more widely adopted as it is a relatively simple system and gives a clear indication of agreement reached between primary and secondary care as to where prescribing responsibility should lie. This categorisation may also aid the commissioning process as funding can be allocated to appropriate budgets.

The perception of cost and workload shifting from secondary to primary care were found to be major barriers to the acceptance of shared care by GPs. It appeared from this work that GPs would be willing to take on more complex treatments in the community if the resource to support this was in place (Appendix 11). This will always be an issue in a NHS which has been plagued by resource constraints from the outset [354] and where the innovations in

therapeutics and technology discussed here are adding substantially to cost pressures to the NHS as a whole.

Primary care prescribing budgets have only relatively recently become cash limited for all GPs, particularly for non-fundholding practices, (abolished with the introduction of PCGs in April 1999). Doctors employed by hospital Trusts are not bound by the same Terms of Service as GPs [355] and Trusts have a statutory responsibility to operate within budget. This has lead, in the past, to GPs sometimes inappropriately taking on prescribing responsibility for drugs such as prostacyclin or octreotide because the local Trust does not have the resource to pay for it. This is in conflict with the General Medical Services, Terms of Service which state that GPs must render to their patients "all necessary and appropriate personal medical services *of the type usually provided by general medical practitioners*" [355]. Work in the South East of England [347] found hospital doctors to be "quite candid in their financial motivation for asking GPs to prescribe specialist medicines".

Responders to both the Health Authority and GP questionnaires expressed a hope that unified budgets may solve some of the problems of perceptions of cost shifting (Appendices 5 and 11). PCGs budgets are now based on unified baseline allocations for hospital and community health services and family health services, general medical services and prescribing costs [356] which has made it easier to allocate resource to the appropriate sector but indicative budgets still exist. Performance against budget such as prescribing incentive schemes in primary care are still based on performance against these indicative budgets. The resource available for service developments is minimal and tends to be directed towards achievement of national targets set by the Department of Health such as waiting list initiatives, the milestones contained in National Service Frameworks and the implementation of NICE guidance. Although it is a government aim to bring high quality, hi-tech care into the community, it is unlikely that resource will be allocated to these developments until there are national targets set for this. The most likely way that these targets will be set is through NICE technology appraisals.

It appears that there is a lack of supporting infrastructure for training of staff such as GPs, district nurse and practice nurses to enable them to take responsibility for hi-tech medicines in the community. An example of this is the recently introduced drug for rheumatoid arthritis, etanercept (Enbrel®, *Wyeth*), that could be given in the community setting, but it is unlikely that GPs will be happy, at least initially, to take on clinical responsibility for the prescribing of such an agent and if this is the case, will nursing staff based in the community be expected to administer the drug? The pharmaceutical industry has looked for ways to get around the short-comings of the NHS by providing specialist trained nurses "free" with the drug, an example of this is for the administration of lanreotide (Somatuline LA®, *Ipsen*) in the patient's home. This is not ideal as it allows the pharmaceutical industry to decide on the appropriate levels of training their staff should receive, staff will be working outside of Trust policies and the company may withdraw the service at any time. More formal agreements of this type may come into being as a result of the current debate on partnerships between the NHS and private sector to provide NHS care.

It may be that as community services are moved into primary care through the formation of new PCTs, a role of specialist community nurses will develop with skills in administering hi-tech or complex therapies, in training patients, trouble-shooting and liaising with specialists in secondary care. This may be through a community-based "consultant" nurse. Alternatively the model of outreach care may be developed further or, as happens currently with HTHH, expertise may be purchased from the private sector.

It is apparent from this research that there is currently no satisfactory mechanism that can be called upon when a GP does not feel qualified to prescribe some of these complex hi-tech therapies on which the patient may be stabilised for long-term treatment (Section 2.2.6.2.4). If the hospital specialist continues to see the patient this could block outpatient appointments for new patients being referred. There is also a practical problem of geography. Currently it seems that patients living in rural areas or remote from a tertiary provider receive an inferior level of care to those patients for whom it is not inconvenient to get to the specialist

centre for follow-up. This inequity is what the present government is trying to eliminate from the NHS.

Prescriptions issued from hospitals that can be dispensed in community pharmacies {FP10(HP)s} have been used in some situations in an effort to overcome this. Electronic prescribing may facilitate this in the future where a hospital specialist could prescribe for a patient electronically and the patient could collect their prescription or have it delivered from their local community pharmacy. Similarly e-pharmacies which were welcomed in the NHS Plan [5] and Pharmacy in the Future, Implementing the NHS Plan [357] might mean that a delivery of the drug, prescribed by the hospital specialist, could be made directly to the patients home. The introduction of repeat dispensing also announced in the NHS Plan [5, 357] could facilitate repeat dispensing of hospital generated prescriptions. It may be appropriate that in the future repeat dispensing is linked to the availability of clinical results such as the system used in hospitals for the dispensing of clozapine (Clozaril®, *Novartis*) prescriptions which may only be dispensed if the results of a blood test are favourable [358].

These solutions however do not overcome the problem that the condition of patients on these complex and often high cost therapies should be adequately reviewed before further supplies of a drug are given. This may be facilitated in the future by video-linked consultations. These have already proved successful in linking rural minor injury units to large accident and emergency departments tapping in to the expertise of the accident and emergency consultants [359]. They have also been used successfully for dermatology consultations from where a GP and patient use video-conferencing facilities for specialist consultations [360] but may not be suitable for all specialties.

The Crown report [109] considered extending prescribing rights to other health professionals and recommended the concept of a "dependant prescriber". These recommendations could be extended for these hi-tech therapies so that GPs could prescribe as "dependant prescribers" on the recommendation of a hospital specialist under a shared care arrangement, with a fast track mechanism for referral back to the specialist for any queries or problems which may arise.

Similarly specialist nurses or pharmacists could continue therapy initiated by a hospital consultant under strict criteria as "dependant prescribers". An example of this would be continued prescribing by a hospital outreach nurse of dornase alpha in cystic fibrosis. The advantage would be that the nurse would be able to review the patient's condition against a set protocol before sanctioning the next prescription but would refer straight back to the specialist if there was any irregularity or cause for concern. In instituting such a mechanism it would be important to ensure that patients treated under this arrangement achieved clinical outcomes comparable to those of patients who were cared for entirely by a hospital specialist.

The success of shared care guidelines already produced has demonstrated that in certain circumstances where cost shifting and work load shifting issues are resolved, the implementation of good quality, locally agreed guidelines with local ownership has allayed many of the concerns of GPs about prescribing complex treatments (section 2.2.6). The GPs surveyed felt that prescribing within the terms of the guidance should be more easily defensible medico-legally, although there have to date been no test cases to confirm this. If the clinical guidance is of high quality, clearly defining the responsibilities of the consultant and the GP, and primary care staff receive adequate training many GPs are happy to take on these new responsibilities. This has been shown to be the case in South and West Devon where there are now 21 guidelines available which are regularly reviewed and updated and are posted on the Health Authority website (www.sw-devon-ha.swest.nhs.uk/HaTeams /Prescribing/sharedcare/ intro.htm).

5.2 Hi-tech Health Care at Home Under EL(95)5

AIM 3

To establish the current position in England on the purchasing and provision of HTHH under EL(95)5 [41].

AIM 4

To evaluate the effectiveness of EL(95)5 [41] in the delivery of HTHH to patients with an emphasis on the role of the pharmacist.

This research found that for hi-tech therapies requiring more complex administration techniques such as intravenous infusions, there are still many barriers that prevent patients receiving appropriate care (sections 3.2.4.1.8 and 3.2.4.2.16). The work has highlighted major inequalities throughout England. An example is the treatment of cystic fibrosis patients. Some patients have their infusions made up in a controlled aseptic environment, with strict quality control measures in place, in special devices or with infusion pumps, which accurately deliver a drug at a set rate and can even provide a history of the infusion parameters. They may have a visiting specialist nurse and 24 hour call out arrangements. However, other patients are supplied with a bag of needles, syringes and vials of a drug and are taught to reconstitute and administer the drug themselves with minimal support (section 3.2.4).

This research found that EL(95)5 [41] did little to introduce competition into the home care market in England. In line with the findings of Short and Norwood [42] it has established that very few Health Authorities have set up competitive tendering exercises to purchase care for patients requiring HTHH. Most continue to roll over existing contracts or arrangements without review (section 3.2.5.2.3). This is probably due to the relatively low numbers of patients in any one Health Authority area meaning that contracting arrangements for HTHH are a low priority.

The care of patients with HTHH was found to be organised on an *ad hoc* basis, by hospitals or Health Authorities with responsibility for commissioning this care. Some large tertiary centres have negotiated their own contracts with commercial providers to provide home TPN, for example, and this has led to problems when the Health Authority responsible for the patient has a different contract (Appendices 19 and 24). This research and that of others [213] has also identified the fact that there is a higher incidence of patients receiving home

infusion therapies such as TPN in patients who live closer to the tertiary centres, a further inequality (Section 3.2.5.1.2).

When HTHH is purchased by Health Authorities or NHS Trusts it was found that service specifications are not always set and when they are, monitoring of compliance with the specifications is scant. The most worrying finding of this research was the lack of almost any formal monitoring of patient outcomes (Section 3.2.6). Some large tertiary providers have begun to monitor certain outcomes and have started to share information on these with other centres to learn from best practice [361]. However this does not apply to the majority of patients receiving HTHH in England. Specialist commissioning teams at a Health Authority level who have little understanding of the clinical outcomes often have responsibility for managing these contracts on a day-to-day basis.

If EL(95)5 [41] had encompassed all HTHH and not just that being prescribed on FP10 prior to 1995 then it's impact may have been greater. As it is, many Health Authorities have not made provision for an increasing number of new patients in diverse therapeutic groups requiring HTHH and so HTHH services have developed in a very fragmented way. Hospital Trusts were found to be unaware of the extent of HTHH being provided by different specialties within the Trust (Appendix 24). If Trusts and Health Authorities are unable to identify which patients are being treated with home infusions, let alone how much it is costing them, it is difficult to see how they can ensure cost effectiveness and that all patients receive a comparable and acceptable level of care.

It is evident from the situation in the USA [134] and other countries such as Canada [117-120], Japan [33, 34] and Italy [126] that more patients could be treated in the home setting. Although hospital at home schemes for older people and those who have had orthopaedic surgery or hysterectomies does seem to have been accepted in England [362-366], hi-tech infusions in the home care setting may be underused [37]. The differences between England and other countries can, to some extent, be explained by different treatment modalities, such as not using TPN in AIDS and cancer patients [38] and less use of intravenous route of administering antibiotics [190]. However a major factor

must be the way the health service is funded in this country. The pressure from patients and payers (purchasers) of health care to reduce hospital length of stay differs from that in the USA. Although the overall efficiency of bed usage in the NHS is increased by treating patients with hi-tech health care at home the overall cost to the NHS is increased [37]. Closing beds is the only way that an overall cost reduction can be realised [40]. However perhaps greater use of HTHH could free up some beds and reduce the need for some of the current investment in increasing inpatient beds.

With the current emphasis on clinical governance [62], to ensure quality of care is high, it seems inconceivable that there are so few mechanisms in place to monitor the outcomes of patients receiving HTHH. This is a comparatively expensive form of treatment with for example one home TPN patient costing in excess of £30,000 a year. However, service specifications are rarely set and there appears to be limited, if any, follow up to ensure that even minimum standards are being met (section 3.2.5.2.5). It has been shown that the number of complications of treatment is inversely related to the experience of the centre providing home TPN [7] and yet the service received by many patients is on an *ad hoc* basis, often from a district general hospital with no previous experience of providing home infusion therapies. Little account is taken of the fact that an apparently expensive provider of HTHH can prove more cost effective in the long term due to fewer complications of treatment [279].

The formation of Primary Care Trusts with full commissioning responsibilities for their smaller populations will mean that the numbers of patients requiring these therapies will be even smaller than those in Health Authority areas and ensuring high quality, cost effective care of these patients may be even less of a priority unless purchasing consortia are formed for this type of commissioning, or care is purchased at a regional specialist commissioning level. This has been considered for drugs such as prostacyclin for primary pulmonary hypertension where the number of patients in a typical Health Authority area would be very small but the cost of treatment is high [367].

This research found that very few Health Authorities were planning for the future growth of treating patients with hi-tech drugs and therapies in the community setting (section 3.2.4.1.6), even though it has been shown to be safe, effective and cost effective in diverse groups of patients [9, 11, 25, 127-132]. Studies have shown that both the quality of life of patients and their families is improved [216, 236, 237, 249, 272]. In a health service where resources are so limited it seems that treating patients in the community negates the need to pay costly hotel charges for patients and decreases the risk of contracting hospital acquired infections. Greater numbers of patients can be treated for the same resource, increasing efficiency, although the overall cost to the NHS is unlikely to decrease. This is an ongoing problem in the NHS as technologies advance then there is a cost associated with providing treatments that were unavailable in the past. Increasing life expectancy is not only associated with increasing costs to the NHS, but a corresponding decrease in the proportion of the population contributing to tax revenues. Health Authorities in their new strategic role need to plan allocation of finances and resources to support an increase in numbers of patients receiving HTHH.

There are various options available in training nursing staff to support patients receiving hi-tech therapies in the community. As with shared care of hi-tech drugs, existing or new community staff could be trained in the care of central lines and use of hi-tech administration techniques, perhaps with consultant nursing specialists to advise and provide support. There could be increasing numbers of outreach staff from hospitals or specialist outreach staff could support community staff, a model which has been shown to work effectively in Oxford [25]. Alternatively partnerships with commercial providers may developed further in a model where the NHS buys in specialist care for these patients. For this to be successful more competitive tendering would have to take place with close monitoring of contracts to introduce greater competition into the home care market. Although this was an aim of EL(95)5 it has so far not been achieved.

The NHS is beginning to embrace new technologies and these could make HTHH safer and more cost effective in the future. As with hi-tech medicines,

video conferencing could be put in place to reduce the number of visits to patients in their homes. Some home care providers are developing this technology for use in the UK home care market [368]. In time training videos will be available in an interactive form on the Internet with staff being available to answer questions online. In the USA ambulatory pumps are already being programmed via telephone lines and data about infusions are being transmitted back to health care professionals for checking and interpretation [369, 370]. It must however be remembered that emotional support is an important part of patient care and patients receiving home infusions have been found to value interaction with and reassurance from both health professionals and other patients in the same position as themselves [236]. This support is also vital to carers who may be taking on a large part of the responsibility for looking after the patient, for coping with the hi-tech devices and coping with the illness of a loved one.

5.2.1 Role of the pharmacist

The pharmacist has an important role to play in the co-ordination and provision of HTHH in the USA and to a lesser extent in the UK. Pharmacists in the UK tend to take on more traditional hospital roles. Some community pharmacists have become involved in the provision of HTHH [268] but this is not currently where their experience lies and it is more appropriately a role for hospital pharmacists or those employed by commercial home care providers. Community pharmacists and primary care pharmacists may have a future role in medicines management initiatives under Pharmacy in the Future – Implementing the NHS plan [357]. The problems with recruitment of staff into hospital pharmacy over recent years [371] have inhibited the development of the role of the pharmacists to taking on more responsibility for the management of patients receiving HTHH. There are examples where pharmacists have had a dedicated role and this has proved successful [269]. Most pharmacists who returned the questionnaire had at least some involvement with co-ordinating the home care programme however it must be remembered that there may be some bias in that pharmacists with more involvement with HTHH programmes may have been more likely to complete and return the questionnaire than those who had little

involvement. It would seem that the pharmacy department is well placed to co-ordinate a home care programme providing services to more than one specialty in the hospital. This has been a major role of pharmacists in the United States. However from the data gathered it was apparent that clinical pharmacists in hospitals often specialise and often set up a programme with just one group of patients in mind (section 3.2.4.2).

Pharmaceutical Advisers to Health Authorities were found to play a major role when contracts have been tendered for in providing some clinical and pharmaceutical expertise (section 3.2.4.2.18). It is unclear with the changing role of Health Authorities who will provide this role in the future. Where service specifications are set both Health Authority Pharmaceutical Advisers and hospital pharmacists are likely to have been involved. A future role may develop along the same lines as the USA with pharmacists playing an important role in continuous quality improvement and outcomes monitoring of HTHH services.

5.3 Benchmarking

AIM 5

To develop a benchmarking tool for use by providers of home infusion therapy to monitor quality of care and improve patient outcomes (Chapter 4, Development of a Benchmarking Tool for the Provision of Home Infusions).

A major finding of this work was the general lack of robust mechanisms for monitoring HTHH services and leading on from this the lack of continuous quality improvement processes. The final part of this work sought to demonstrate the possibility of monitoring quality and outcomes of HTHH in England by the development of a tool which could be used in benchmarking home infusion services in order to identify, and learn from, best practice.

It is vital that patient outcomes are monitored and that those centres with greatest experience and with lower complication rates share through benchmarking their experiences, giving advice on procedures and processes that should be followed to allow others to achieve comparable outcomes. It is unacceptable that within

the NHS learning is not shared. Learning must be shared in an open way even when commercial providers are contracted to provide care on behalf of the NHS. An organisation with a memory [372] goes one step towards the NHS learning from critical incidents and errors and the philosophy of beacon sites [373] has started to create a culture of learning from best practice within the NHS. However, neither of these initiatives appears to have impacted on the provision of HTHH under EL(95)5 (section 3.2.5.2.6.5).

Now that technology exists whereby information can be easily stored, manipulated and used to identify best practice and improve patient care, many would suggest that it is inexcusable not to do so. Electronic communication and access to data can be used to make communication easier and more timely but this is not current practice in the NHS. It can be seen from the benchmarking programme developed in this study, that storing information around a patient rather than a provider is relatively simple to achieve and could lead to better communication and learning from current best practice. The use of a model such as this in the provision of HTHH would require investment in both hardware and software which was compatible across primary care, secondary care and commercial sectors. When security issues around patient data are resolved NHS net could provide the vehicle for doing this.

A major step towards a wider culture of benchmarking would be to develop a robust set of quality or outcome indicators. Information from different centres must be comparable if it is to be used for this purpose and so the first step would be to identify a set of benchmarks and then define them to ensure that like is compared with like. Difficulties in achieving this have been demonstrated the USA where a set of indicators underwent alpha [313] then beta testing but were not developed further [271]. Insurers and other payers eventually drove home care providers to register with commercial benchmarking organisations which developed their own benchmarks and indicators. Examples of some crude indicators have been included in the demonstration tool (Appendix 25) but would require significant refinement for future use.

A factor that is difficult to overcome is ensuring that complications are not effectively double counted or centres are not presented negatively for maintaining close contact with the patient and keeping better records. A centre that diligently records all contact with patients and all potential problems can easily appear to be performing badly compared to a centre who do not keep such detailed records. It is vital to ensure that like is compared with like and that indicators are interpreted and rather than being used as face value. They should be used to ensure that relevant questions are asked and can be answered satisfactorily.

Advantages of the use of a tool similar to that in Appendix 25 would be that all staff involved in the care of a patient at home would have access to up-to-date, accurate information. This would lead to decreased risk of error or omission caused by lack of timely information or poor communication between health professionals and ancillary staff, delivery drivers etc. The patient would receive consistent information from all involved in their care and data could be used to monitor quality of care and patient outcomes. The database could subsequently be queried for the purpose of audit, demonstrating compliance with service specifications, identifying the effects of changes in process and benchmarking.

6 Conclusion

6.1 Shared Care

6.1.1 Main Findings

I. The situation in 1996/7 was that shared care guidelines had been adopted to a limited degree in most areas of the country to resolve interface prescribing issues.

II. Shared care guidelines were found to have been produced, in general, for higher cost and hi-tech therapies where there has been contention over where prescribing responsibility should lie.

III. Successful models were those where there was local ownership of the process of developing the guidelines from both primary and secondary care.

IV. Processes which improved communication and collaboration between primary and secondary care both in the agreement of the guidelines and in their implementation were the most successful, particularly where the guidelines clearly defined respective responsibilities of the clinicians involved.

V. Major barriers to the successful implementation of shared care initiatives were the perception of cost shifting and workload shifting from primary to secondary care, lack of recognition that clinical responsibility is not separable from prescribing responsibility, poor communication, and problems caused by the practicalities of sharing care with a tertiary provider.

6.1.2 Recommendations

I. Further shared care guidelines for complex specialist initiated therapies should be developed to facilitate prescribing in the community setting.

II. The process for agreeing guidelines should be one that encourages communication and agreement at the primary/ secondary care interface.

III. Mechanisms should be put in place to enable local prescribing of complex or hi-tech therapies whilst allowing tertiary (or secondary) care specialists to maintain overall clinical responsibility.

6.2 Hi-tech Health Care at Home

6.2.1 Main Findings

I. The incentive, found in other countries, to discharge patients from hospital in order to reduce hotel costs by providing HTHH is not present in England due to differences in the way the NHS is funded.

II. Considerable variation occurred throughout England regarding mechanisms in place for the purchasing and provision of HTHH under EL(95)5 leading to inequitable service provision.

III. EL(95)5 did little to introduce competition into the home care market as most HAs have not put the provision of these services out to tender and have no plan for future provision or development of this model of health care delivery.

IV. Service specifications are rarely set and patient outcomes or quality of the care are seldom monitored.

V. By directing HAs to top-slice primary care prescribing budgets but not secondary care budgets to provide HTHH, EL(95)5 caused provision of HTHH to become fragmented.

VI. NHS Trusts were found to have an uncoordinated approach to providing HTHH across different clinical specialties.

VII. Pharmacists currently play a central role in the provision of HTHH in England but experience in the USA has shown that their expertise could be used further, particularly in taking a professional lead of continuous quality improvement and outcomes monitoring.

6.2.2 Recommendations

I. A plan is required for introduction and development of HTHH in a more co-ordinated manner across the NHS.

II. A system should be introduced whereby all HTHH is purchased via the same mechanism, perhaps through groups of purchasers, such as consortia of Primary Care Trusts.

III. Service specifications should be set and compliance closely monitored. Quality of care and patient outcomes should be continuously reviewed and improved upon. A quality-monitoring tool is required to facilitate this.

IV. Greater use should be made of the clinical skills of pharmacists to improve the quality, co-ordination and monitoring of HTHH services.

6.3 Benchmarking Hi-tech Health Care at Home

6.3.1 Main Findings

I. A benchmarking tool was developed which shows the possibilities of
- storing data regarding patients receiving HTHH
- improving communication between health care professionals and the patient
- allowing monitoring against service specifications
- focusing continuous quality improvement initiatives
- providing benchmarking data

– identifying staff training needs.

II. Development of more robust quality or outcome indicators would require a wider pool of patient data and substantial further work. The benchmarking tool could be used to establish, test and validate these.

6.3.2 Recommendations

I. It is recommended that a database be professionally developed incorporating the features outlined above.

II. Wider use of such a programme through its incorporation onto NHS net would provide an excellent way of generating a sufficient database to allow the benefits to be fully realised. Commercial providers would need access to this facility.

III. A robust set of quality or outcome indicators for HTHH should be developed and agreed to allow benchmarking of home infusion services.

7 Presentation and Publication of results

Data from this project has been presented at both national and international conferences and published in both British and American journals.

Information from the Health Authority survey on the current position regarding HTHH in England was presented orally at the 25th Anniversary, Clinical Pharmacy and Pharmaceutical Care International Meeting, Barcelona, June 4th-6th 1998.

Results of both the national survey of Health Authorities and the local survey of South and West Devon GPs on shared care was presented orally at the 3rd National Prescribing Centre Conference for Health Authority Advisers, Hinkley, 18th-19th June 1998.

An interim analysis of the data obtained from the Health Authority questionnaire was presented as a poster at the British Pharmaceutical Conference, Eastbourne, September 8th-11th 1998 and published in a Pharmacy Practice Research Supplement to the Pharmaceutical Journal [284] (Appendix 28). More questionnaires were returned after this was published.

A poster showing the combined results of the Health Authority, Trust and Commercial provider surveys on HTHH was presented at the American Society of Health Systems Pharmacists Section of Home Care Practitioners Home, Hospice and Long Term Care Conference, Chicago, 31st July – 2nd August 1999 and a paper was subsequently published in the American Journal of Health Systems Pharmacy [331] (Appendix 29).

An analysis of the role of the pharmacist in HTHH from the Trust questionnaire was presented as a poster at the British Pharmaceutical Conference, Cardiff, 13th-15th September 1999 and was also published in a Practice Research Supplement to the Pharmaceutical Journal [286] (Appendix 30).

The benchmarking tool developed was demonstrated at a workshop of the first UK inter-disciplinary Home Care Conference, At Home '99, Advances in Treatments at Home, London, 10^{th}-12^{th} November 1999.

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APPENDICES

APPENDIX

1

Pharmacy Office,
Mount Gould Hospital,
Mount Gould Road,
Plymouth.
PL4 7QD
☎01752-272588

25th April 1997

Dear Colleague,

I am a pharmacist working in Plymouth and am researching the current position in the United Kingdom on 'shared care' and 'hi-tech health care at home'. The work is for an M.Phil. project registered with the University of Plymouth and sponsored by the NHS Executive.

My aims are to find out, for shared care

- which areas have shared care committees
- who is represented on them
- what different areas have managed to achieve (with or without a committee)
- what are the future goals in the area of shared care
- which aspects of shared care have been successful
- which aspects have been difficult or unsuccessful

and for hi-tech healthcare at home

- to what extent patients are being treated in their homes with 'hi-tech' therapies
- who is currently providing the various aspects of their care
- to what extent are primary care professionals involved with their care
- whether there are geographical or demographic trends in 'hi-tech' home care in England
- how much is being invested into the caring for these patients at home nationally

I will be sending this questionnaire to medical and/or pharmaceutical advisors of all of the Health Authorities in England. The information I receive will be used with other information on demographics, expenditure etc to see if there are any correlations between the data you provide and other factors.

I intend to publish an analysis of the information I obtain in a relevant health journal. The data will be combined so that data from individual health authorities will not be identifiable. I will be happy to send responders a summary of my findings.

If you would like more information about my study or these questionairre please contact me (01752-272588).

The questionnaire will take approximately x minutes to complete. If you are unable to complete the questionnaire please pass it on to someone else who may be able to.

Thank you very much for your help.

Yours faithfully

Jill LOADER (Miss)
Research Pharmacist

CONFIDENTIAL

Survey number | | | | | | |

Shared Care And Hi-Tech Health Care At Home Questionnaire

The questionnaire will take approximately x minutes to complete. If you do not know the answer to a question just leave it blank and go on to the next one. If there is someone that I can contact who might know any missing answers please give a contact name and telephone number.

To complete the questionnaire please write in the boxes provided, delete yes or no as required or tick the appropriate box. If more than one answer applies please tick all appropriate boxes. If you feel an answer might need an explanation, please feel free to add additional comments.

Thank you

Please return in the stamped addressed envelope to:
Miss Jill Loader, Pharmacy Office, Mount Gould Hospital, Mount Gould Rd, Plymouth PL4 7QD
☎ 01752-272588

What is your job title? *(please tick)*

Medical Advisor ☐

Pharmaceutical Advisor ☐

Other, please specify ☐

Section 1

Shared Care

Question 1
Do you have a shared care committee or equivalent in your area? *(please ring)* yes/ no

Question 2
If yes, which professional groups are represented on the committee?
If no, go to question 4 *(tick as many boxes as necessary)*

General Practitioners	☐	Local Medical Committee Representatives	☐
Health Authority Consultants in Public Health	☐	Local Prescribing Committee Representatives	☐
Health Authority Medical Advisers	☐	Trust Consultants	☐
Health Authority Pharmaceutical Advisers	☐	Trust Pharmacy Representatives	☐
Other, please specify (in box below)	☐	Contracting Managers/Administration Staff	☐

Question 3
a) When was the shared care committee formed? *(year)*

b) What was the subject of the first guideline it ageed?

c) When was it produced? *(year)*

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Survey number | | | | | | |

Question 4

Do you have a shared care guideline in your area for the following drugs/ conditions?
(tick as many boxes as necessary)

drug/condition	agreed and in use	informally agreed	being developed
erythropoetin	☐	☐	☐
cyclosporin	☐	☐	☐
alpha interferon	☐	☐	☐
beta interferon	☐	☐	☐
methotrexate	☐	☐	☐
home antibiotics	☐	☐	☐
home parenteral nutrition	☐	☐	☐
home chemotherapy	☐	☐	☐
enteral feeding	☐	☐	☐
anticoagulants	☐	☐	☐
disease modifying drugs rheumatology	☐	☐	☐
diabetes	☐	☐	☐
hypertension	☐	☐	☐
AIDS/HIV	☐	☐	☐
infertility	☐	☐	☐
cystic fibrosis	☐	☐	☐
epilepsy	☐	☐	☐
psychiatric disorders	☐	☐	☐
terminal illness	☐	☐	☐
other, please specify	☐	☐	☐
	☐	☐	☐
.....	☐	☐	☐
.....	☐	☐	☐
.....	☐	☐	☐
.....	☐	☐	☐
.....	☐	☐	☐
.....	☐	☐	☐
.....	☐	☐	☐
.....	☐	☐	☐
.....	☐	☐	☐

Question 5
Which aspects of shared care have been successful in your area?

Question 6
Which aspects of shared care have been difficult or problematic?

Question 7
Any further comments you would like to make about shared care?

ection 2

Hi-tech health care at home

uestion 1

ow many patients under the care of your Heath Authority currently receive hi-tech health care at home, accordance with EL(95)5, in the following groups?

	number over the past 3 years (including current)	current number	expenditure March '96-April'97
Patients with renal failure receiving CAPD			
Cystic fibrosis patients receiving intravenous or nebulised antibiotics			
Cancer patients receiving intravenous chemotherapy agents			
HIV patients receiving intravenous or nebulised anti-infectives			
Patients receiving TPN or various types of specialised enteral feed			
Thallassaemics receiving desferrioxamine			
Other, eg antibiotics for other conditions, asthma patients, please specify.			

uestion 2

Who is currently responsible for contracting for 'hi-tech home therapy'?

uestion 3

o you know of any fundholding GPs in your area who directly purchase hi-tech health care at ome for their patients? *(please ring)* yes/ no

so please specify for which condition, from whom do they purchase this care and for how any patients.

Question 4

Who provides the following to the patients receiving home care in your area? *(Please tick as many as necessary)*

	nursing services	drugs	other equipment/ supplies
commercial home care company	☐	☐	☐
acute trust	☐	☐	☐
community trust	☐	☐	☐
combined acute/community trust	☐	☐	☐
combination of the above, please specify	☐	☐	☐

other organisation, please specify	☐	☐	☐

Question 5

Does the health authority have future plans for the care of these patients? *(please ring)* yes/ no

If yes, who do you plan to contract with *(please tick)*

- commercial home care company ☐
- hospital trust ☐
- community trust ☐
- combination of the above, please specify ☐

- other, please specify ☐

uestion 6

hich aspects of 'hi-tech healthcare at home' have been successful in your area?

uestion 7

Which aspects of hi-tech health care at home have been difficult or problematic in your area?

Question 8

Further comments on hi-tech health care at home

Please tick if you would like a summary of the results obtained from this questionairre ☐

Your name and address (if you would like to give it)

Thank you for spending the time to complete this questionnaire

Please return in the stamped addressed envelope to:
Miss Jill Loader, Pharmacy Office, Mount Gould Hospital, Mount Gould Rd, Plymouth PL4 7QD
☎ 01752-272588

APPENDIX

2

Pharmacy Office,
Mount Gould Hospital,
Mount Gould Road,
Plymouth.
PL4 7QD
☎01752-272588
12th August1997

Dear Colleague,

I am a pharmacist working in Plymouth and am researching the current position in the United Kingdom on 'shared care' between primary and secondary care and 'hi-tech health care at home'. The work is for an M.Phil. project registered with the University of Plymouth and sponsored by the NHS Executive.

My aims are to find out, for shared care

- which areas have managed to develop and implement shared care guidelines
- who is involved with drawing up and agreeing the guidelines
- whether a specific committee has been formed to facilitate the introduction of shared care
- what are the future goals in the area of shared care
- which aspects of shared care have been successful
- which aspects have been difficult or unsuccessful

and for hi-tech healthcare at home

- to what extent patients are being treated in their homes with 'hi-tech' therapies
- who is currently providing the various aspects of their care
- whether there are geographical or demographic trends in 'hi-tech' home care in England
- how much is being invested into the caring for these patients at home nationally

I will be sending this questionnaire to medical and/or pharmaceutical advisers of all of the Health Authorities in England. The information I receive will be used with other information on demographics, expenditure etc to see if there are any correlations between the data you provide and other factors.

I intend to publish an analysis of the information I obtain in a relevant health journal. The data will be combined so that data from individual health authorities will not be identifiable. I will be happy to send responders a summary of my findings.

The questionnaire will take approximately 10 minutes to complete. If you are unable to complete the questionnaire please pass it on to someone else who may be able to.

Thank you very much for your help.

Yours faithfully

Miss Jill Loader, Research Pharmacist

CONFIDENTIAL

Survey number						

Shared Care and Hi-tech Health Care at Home Questionnaire

The questionnaire will take approximately 10 minutes to complete. If you do not know the answer to a question just leave it blank and go on to the next one. If there is someone that I can contact who might know any missing answers please give a contact name and telephone number.

To complete the questionnaire please write in the boxes provided, delete yes or no as required or tick the appropriate box. If more than one answer applies please tick all appropriate boxes. If you feel an answer might need an explanation, please feel free to add additional comments.

Thank you

Please return in the stamped addressed envelope to:
Miss Jill Loader, Research Pharmacist, Pharmacy Department,
Derriford Hospital, Plymouth, PL6 8DH.
☎ 01752-272588

Section 1

Shared Care

1. Do you have any guidelines in your area for sharing the care of patients between primary and secondary care? yes/ no

If yes, for which drugs/conditions? (tick the appropriate box)

drug/condition	agreed and in use	informally agreed	being developed
erythropoetin	☐	☐	☐
cyclosporin	☐	☐	☐
alpha interferon	☐	☐	☐
beta interferon	☐	☐	☐
dornase alpha	☐	☐	☐
donepezil	☐	☐	☐
riluzole	☐	☐	☐
home antibiotics	☐	☐	☐
home parenteral nutrition	☐	☐	☐
home chemotherapy	☐	☐	☐
enteral feeding	☐	☐	☐
anticoagulants	☐	☐	☐
rheumatology	☐	☐	☐
diabetes	☐	☐	☐
AIDS/HIV	☐	☐	☐
infertility	☐	☐	☐
other, please specify	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐
	☐	☐	☐

2. Who is responsible for agreeing and implementing shared care guidelines?

- a shared care committee ❑
- a trust drug and therapeutics committee ❑
- a health authority prescribing committee ❑
- other, please specify ❑

3. Which professional groups are represented on the committee?

General Practitioners	❑	Local Medical Committee Representatives	❑
Health Authority Consultants in Public Health	❑	Local Pharmaceutical Committee Representatives	❑
Health Authority Medical Advisers	❑	Trust Consultants	❑
Health Authority Pharmaceutical Advisers	❑	Trust Pharmacy Representatives	❑
Contracting Managers/Administration Staff	❑	Other, please specify *(in box below)*	❑

4. Which aspects of shared care have been successful in your area?

5. Which aspects of shared care have been difficult or problematic?

6. Any further comments you would like to make about shared care?

Section 2

Hi-tech health care at home

1. How many patients under the care of your Heath Authority currently receive hi-tech health care at home, in accordance with EL(95)5, in the following groups?

	current number (approximately)	approximate annual expenditure (will remain anonymous) under £50K	£50-£100K	£100-£200K	over £200K
• Cystic fibrosis patients receiving intravenous or nebulised antibiotics					
• Cancer patients receiving intravenous chemotherapy agents					
• HIV patients receiving intravenous or nebulised anti-infectives					
• Patients receiving TPN or various types of specialised enteral feed					
• Thallassaemics receiving desferrioxamine					
• Other, eg antibiotics for other conditions, asthma patients, *please specify*.					

2. Is 'hi-tech health care at home' as specified by EL(95)5 contracted as part of a bulk contract with a provider or as a separate contract by your health authority?

3. Do you know of any fundholding GPs in your area who directly purchase hi-tech health care at home for their patients? *(please ring)* **yes/no**

4. Who provides the following to the patients receiving home care in your area? *(Please tick as many as necessary)*

	nursing services	drugs	other equipment/ supplies
commercial home care company	❑	❑	❑
acute trust	❑	❑	❑
community trust	❑	❑	❑
combined acute/community trust	❑	❑	❑
combination of the above, please specify	❑	❑	❑

other organisation, please specify ❑ ❑ ❑

5. Does the health authority have future plans for the care of these patients? *(please ring)* **yes/ no**

6. Which aspects of 'hi-tech healthcare at home' have been successful in your area?

7. Which aspects of hi-tech health care at home have been difficult or problematic in your area?

8. Further comments on hi-tech health care at home

What is your job title? *(please tick)*

Medical Adviser ☐

Pharmaceutical Adviser ☐

Other, please specify ☐

Please tick if you would like a summary of the results obtained from this questionnaire ☐

Your name and address (if you would like to give it)

Thank you for completing this questionnaire!

Please return in the stamped addressed envelope to:
Miss Jill Loader, Research Pharmacist, Pharmacy Department,
Derriford Hospital, Plymouth. PL6 8DH.
☎ 01752-272588

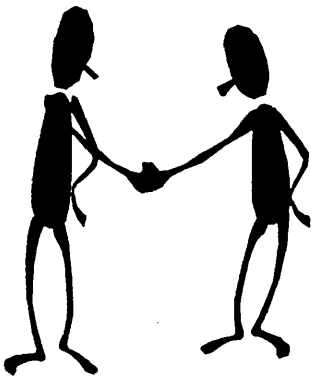
APPENDIX

3

pilot.

Survey No

Shared Care Survey



In November 1991 the NHS Executive produced guidance on the responsibility for prescribing at the hospital/general practitioner interface in the form of EL(91)127. It reinforced the basic premise that the doctor who has clinical responsibility for the patient should prescribe and focused on the concept of shared care, emphasising the need for proper hand over procedures from hospitals to make sure that the general practitioner was properly informed and could monitor treatment and adjust dose if necessary based on a protocol for treatment.

As a result of this guidance the South and West Devon, Cornwall and Isles of Scilly Shared Care Working Group was formed and has been working on the development of such shared care guidelines. The first few of which you should have received.

I would be very grateful for some feedback from you about the locally agreed guidelines and the concept of shared care. All information gathered will be treated as strictly confidential. The survey number on the top of this form will be used purely for a second mailing to non-responders. The data collected will be used to compare GP opinions on shared care with those of Health Authorities for a MPhil project sponsored by the NHSE.

This brief questionnaire should take less than 5 minutes to complete.

Many thanks for your help!

Please return in the stamped addressed envelope provided to:
Jill Loader, Research Pharmacist, Plymouth Post Graduate Medical School,
Pharmacy, Level 5, Derriford Hospital, Plymouth. PL6 8DH

pilot.

Section 1

Some questions about your experience of the locally agreed shared care guidelines.

Question 1

Have you ever seen a shared care guideline produced by the South & West Devon, Cornwall & Isles of Scilly Working Group? *(tick the appropriate box)*

- ☐ I have used one or more of the guidelines
- ☐ I have seen a guideline but never used one
- ☐ I have never seen one

Question 2

If you have read the guidelines, do you think the information they contain is *(tick one in each row)*

☐ very useful	☐ not very useful	☐ of some use
☐ too complex	☐ not complex enough	☐ about right
☐ too long	☐ not long enough	☐ about right

Question 3

a) If you are asked to prescribe specialist drugs initiated by a secondary care colleague of which you have little experience, do you

- ☐ generally prescribe it
- ☐ ask the hospital consultant to prescribe it
- ☐ prescribe it only if the patient would have difficulty obtaining supplies otherwise
- ☐ prescribe it, providing you have a recommendation from the hospital in writing
- ☐ prescribe it if there is a shared care guideline
- ☐ prescribe it only if the request is accompanied by sufficient clinical information
- ☐ other, please specify .....

.....

.....

.....

.....

Question 5

What drugs/diseases would you most like to have a shared care guideline for? *(please specify below)*

.....

.....

.....

.....

pilot.

Section 2

Some questions about your views on the concept of shared care.

Question 1

Please tick the most appropriate box for each statement

	strongly agree	agree	undecided	disagree	strongly disagree
• Shared care is a useful idea so primary and secondary care clinicians are aware of their respective responsibilities when sharing the care of a patient.	❑	❑	❑	❑	❑
• Shared care is the development of something that has been going on for years.	❑	❑	❑	❑	❑
• Shared care is about transferring care from secondary into primary care.	❑	❑	❑	❑	❑
• Shared care guidelines empower GPs to prescribe more complex medication.	❑	❑	❑	❑	❑
• Shared care guidelines give GPs the opportunity to opt out of sharing the care of a patient for whom they do not feel qualified to prescribe.	❑	❑	❑	❑	❑
• Shared care is about cost shifting to primary care.	❑	❑	❑	❑	❑
• The shared care working group is able to suggest that a drug is unsuitable for prescribing in primary care.	❑	❑	❑	❑	❑
• The concept of shared care is a medico-legal problem.	❑	❑	❑	❑	❑
• Shared care guidelines give GPs the opportunity to opt in to sharing the care of a patient for whom they do feel qualified to prescribe with use of the guideline.	❑	❑	❑	❑	❑

pilot.

Have you any further comments regarding shared care?

I would like a summary of your findings. *(Please tick)* ☐

Thank you very much for your time.

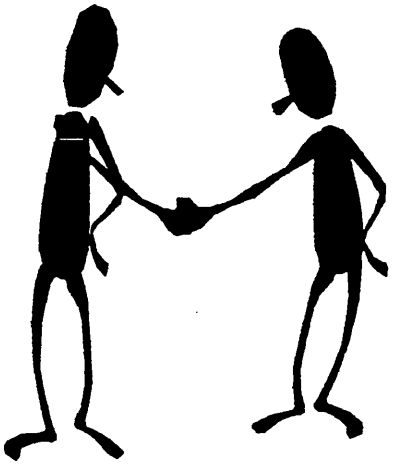
Please return in the stamped addressed envelope provided to:
Jill Loader, Research Pharmacist, Plymouth Post Graduate Medical School,
Pharmacy, Level 5, Derriford Hospital, Plymouth. PL6 8DH

APPENDIX

4

CONFIDENTIAL Survey No

Shared Care Survey



The NHS Executive produced guidance on the responsibility for prescribing at the hospital/general practitioner interface in the form of EL(91)127.

EL(91)127

- *reinforced the premise that the doctor who has clinical responsibility for the patient should prescribe*
- *focused on the concept of shared care*
- *emphasised the need for proper hand over procedures from hospitals to ensure the GP was fully informed*
- *highlighted the need for protocols which the GP could use to monitor treatment and adjust doses if necessary.*

Following this guidance the South and West Devon, Cornwall and Isles of Scilly Shared Care Working Group was formed and has been working on the development of such shared care guidelines. You should already have received a folder containing the first agreed guidelines.

I would be very grateful for some feedback from you about the locally agreed guidelines and the concept of shared care. All information gathered will be treated as strictly confidential. The survey number on the top of this form will be used purely for a second mailing to non-responders and to send out a summary of my findings where requested. The data collected will be used to compare GP opinions on shared care with those of Health Authorities, obtained from a national survey, for a MPhil project sponsored by the NHSE.

This brief questionnaire should take less than 5 minutes to complete.

Many thanks for your help!

Please return in the stamped addressed envelope provided to:
Jill Loader, Research Pharmacist, Plymouth Post Graduate Medical School,
Pharmacy, Level 5, Derriford Hospital, Plymouth, PL6 8DH.

Section 1

Some questions about your experience of the locally agreed shared care guidelines.

Question 1

Have you ever seen a shared care guideline produced by the South & West Devon, Cornwall & Isles of Scilly Working Group? *(tick the appropriate box)*

- ☐ I have used one or more of the guidelines
- ☐ I have seen a guideline but never used one
- ☐ I have never seen one

Question 2

If you have read the guidelines, do you think the information they contain is *(tick one in each row)*

a)	☐ very useful	☐ of some use	☐ not very useful
b)	☐ too complex	☐ about right	☐ not complex enough
c)	☐ too long	☐ about right	☐ not long enough

Question 3

a) If you are asked to prescribe specialist drugs initiated by a secondary care colleague of which you have little experience, do you generally: *(tick one or more)*

- ☐ prescribe it
- ☐ ask the hospital consultant to prescribe it
- ☐ prescribe it only if the patient would have difficulty obtaining supplies otherwise
- ☐ prescribe it, providing you have a recommendation from the hospital in writing
- ☐ prescribe it if there is a shared care guideline
- ☐ prescribe it providing it is not too expensive
- ☐ prescribe it only if the request is accompanied by sufficient clinical information
- ☐ other, please specify .....

.....

.....

.....

.....

Question 5

What drugs/diseases would you most like to have a shared care guideline for eg. risperidone, DMARDs ?*(please specify below)*

Section 2

Some questions about your views on the concept of shared care.

Question 1

Please tick the most appropriate box for each statement

	strongly agree	agree	undecided	disagree	strongly disagree
• Shared care is a useful means of defining the respective responsibilities of primary and secondary care physicians.	❑	❑	❑	❑	❑
• Shared care is the development of something that has been going on for years.	❑	❑	❑	❑	❑
• Shared care is about transferring care from secondary into primary care.	❑	❑	❑	❑	❑
• Shared care guidelines empower GPs to prescribe more complex medication.	❑	❑	❑	❑	❑
• Shared care guidelines give GPs the opportunity to opt out of sharing the care of a patient for whom they do not feel qualified to prescribe.	❑	❑	❑	❑	❑
• Shared care is about cost shifting to primary care.	❑	❑	❑	❑	❑
• The shared care working group is able to suggest that a drug is unsuitable for prescribing in primary care.	❑	❑	❑	❑	❑
• There are unresolved medico-legal problems when sharing the care of a patient with a secondary care colleague.	❑	❑	❑	❑	❑
• Using shared care guidelines gives GPs the opportunity to opt in to sharing the care of a patient for whom they do feel they have the experience to prescribe.	❑	❑	❑	❑	❑

Have you any further comments regarding shared care?

I would like a summary of your findings. *(Please tick)* ☐

Thank you very much for your time.

Please return in the stamped addressed envelope provided to:
Jill Loader, Research Pharmacist, Plymouth Post Graduate Medical School,
Pharmacy, Level 5, Derriford Hospital, Plymouth. PL6 8DH

(May 1998)

APPENDIX

5

Data for Coding

Thank you very much for agreeing to help code this qualitative data obtained from a questionnaire survey of Health Authorities in England. The questionnaires were completed by either the Pharmaceutical Adviser, Medical Adviser or Contracts Manager of the Health Authority. The response rate to the questionnaire was 87%. I enclose a copy of the questionnaire sent out and copies of the original answers, in hand written form will be available to you at the meeting. The following are the answers to Section 1, questions 4, 5 & 6.

Abbreviations :
GP = General Practitioner, HA = Health Authority

Qualitative Comments Regarding Shared

Survey Number	1
4 Successful	Joint approach between GPs/Trusts and HA.
5 Difficult	Life may be easier if we had joint primary and secondary care drug budgets!!
6 Further comments	

Survey Number	2
4 Successful	
5 Difficult	
6 Further comments	Not sure what you mean by 'shared care'. We have generic guidelines for GPs who are asked to prescribe specialist initiated drugs.

Survey Number	3 and 8 (2 people completed the survey for this HA)
4 Successful whether framework	3) The committee has been useful in providing clear guidance to GPs on drugs are appropriate for primary care prescribing and giving a clear around transfer of care. 8) It's hard to say, some protocols developed but they don't seem to see the light of day.
5 Difficult	3) Often contentious debate between the HA and Trust consultants around the evidence base for the drugs under discussion. Has raised difficult issues around funding. Getting consultants from our 5 Trusts(!) to all agree to a shared care protocol. 8) Getting the consultants to understand that prescribing and clinical responsibility are attached, not separable.
6 Further comments	3) We prefer the term "Transfer of Care" rather than "shared care" - (if a GP is accepting responsibility for drugs discussed within the committee they also accept clinical responsibility).

Survey Number	5
4 Successful	Development of a traffic light system where; red = hospital only prescribing, amber = initially hospital-only for specified period. Transfer of care after initial period with appropriate shared care arrangements in place and agreement of GP, green = prescribe in primary and secondary care.
5 Difficult	Development of specific guidelines/protocols for individual preparations. A 'generic' framework setting out information to be included is currently being prepared.
6 Further comments	Shared care is not about cost-shifting but about ensuring that responsibility for prescribing is consistent with clinician responsibility and establishing appropriate transfer of care arrangements. Development of a shared care protocol/guidance is not in itself a shared care agreement. Shared care must be agreed by a clinician and GP on an individual basis with the transfer of care being supported by the protocol.
Survey Number	6
4 Successful	
5 Difficult	Within the current climate no area of shared care is easy - the GPs are revolting! The DTC for this HA has not so much developed guidelines for shared care as put forward advise as to whether or not to prescribe (and who should prescribe - consultant or GP) and made relevant suggestions as to what to expect from a share care agreement.
6 Further comments	Although one of the Trusts in this area have put together a series of shared care guidelines - they are not too successful. The emphasis is on empowering GPs to look at whether to take on prescribing and if so to ensure they have a written shared care agreement with a proper role in the management.
Survey Number	16
4 Successful	
5 Difficult	
6 Further comments	
Survey Number	17
4 Successful	
5 Difficult	
6 Further comments	
Survey Number	21
4 Successful	Working with the .....*(neighbouring)* HA generally.
5 Difficult	LMC core/non-core payment for work undertaken. Dealing with more than one provider.
6 Further comments	

Survey Number	23
4 Successful	Anything cheap.
5 Difficult	Anything expensive! Also areas such as beta interferon where the local consultants don't wish to use the drug.
6 Further comments	

Survey Number	24
4 Successful	Helps transfer of prescribing responsibility - GPs feel more comfortable.
5 Difficult	Persuading consultants of need to write them.
6 Further comments	

Survey Number	25
4 Successful	Unsure
5 Difficult	Seen as a cost shifting exercise and so not fully developed
6 Further comments	Not always done on appropriate drugs.

Survey Number	26
4 Successful	Through direct contract negotiations. Individual case informal agreements.
5 Difficult	Bureaucratic policies. Who will 'pay' for the drug. GPs view shared care as "dumping" drug costs on them.
6 Further comments	

Survey Number	27
4 Successful	
5 Difficult	
6 Further comments	

Survey Number	29
4 Successful	Home Parenteral Nutrition
5 Difficult	
6 Further comments	

Survey Number 30	
4 Successful	We successfully produced a document outlining process and the drugs concerned.
5 Difficult	We have been unsuccessful in implementation. The committee was not seen to be "high-powered enough". Trust chief pharmacists seem unable to implement formulary management at hospital level. Anything which has involved more than one Trust. Tertiary care providers where we are minor purchasers.
6 Further comments	

Survey Number	31
4 Successful	The areas in which shared care has worked are either; a) Those already in place before 1995 ie EPO in dialysis patients b) Those introduced as a consequence of EL(95)5.
5 Difficult	Virtually all other areas but especially neurology/psychiatry drugs.
6 Further comments	Developing shared care guidelines is an important part of this Authority's approach to the managed introduction of new drugs and technologies.
Survey Number	32
4 Successful	Not much.
5 Difficult	Consultants don't know what GPs need to know to take on clinical responsibility.
6 Further comments	
Survey Number	33
4 Successful	Agreeing a policy for defining shared care drugs and criteria for developing "shared care" policies.
5 Difficult	Agreeing which drugs to include. The whole area is a nightmare!
6 Further comments	
Survey Number	34
4 Successful	
5 Difficult	All, GPs see it as cost shifting. Really we are in the early stages of development of shared care guidelines. We may introduce a traffic light system for prescribing like they are doing in ..... HA.
6 Further comments	
Survey Number	35
4 Successful	Measured introduction of some of the drugs previously mentioned eg beta-interferon.
5 Difficult	Often identifying the need for protocols. Attitude is often "I am a consultant, so do as I say and prescribe drug x because the hospital cannot afford it!"
6 Further comments	
Survey Number	36
4 Successful	donepezil, riluzole, infertility
5 Difficult	beta interferon
6 Further comments	
Survey Number	37
4 Successful	Constructive discussion. Understanding of problems facing GPs by consultants.
5 Difficult	Prescribing outside product licence. Shared care vs cost-shifting.
6 Further comments	Care can really only be "shared" when GP's have the ability to alter dosage/treatment regimes - otherwise cost-shifting exercise.

Survey Number	38
4 Successful	
5 Difficult	
6 Further comments	

Survey Number	39
4 Successful	Development and agreement on the principles and recommendations as to how shared care prescribing should be undertaken.
5 Difficult	Ownership, developing specific guidelines for drugs/conditions.
6 Further comments	

Survey Number	40
4 Successful	Gaining joint agreement from GPs on the key drugs for hospital only prescribing and top slicing GP budgets to pay for the change. (100% GP fundholders in HA)
5 Difficult	Gaining joint agreement with other HAs so that approaches are standardised for Trusts. Communicating the facts (eg funding will follow from GPs to Trusts, FP10(HP)s will avoid need for patients to get supplies from hospital) to Trusts and consultants in particular.
6 Further comments	Clinical and prescribing responsibility can not be separated. Must therefore TRANSFER rather than SHARE these aspects of care between primary and secondary care. There will always be a need to update positions as clinical knowledge advances and GPs gain confidence and become increasingly competent to prescribe.

Survey Number	41
4 Successful	Diabetes
5 Difficult to	with high cost drugs GPs suspect they are being asked to 'share care' merely fund the medication. Often this is correct.
6 Further comments	

Survey Number	42
4 Successful	Although I have not seen any written guidelines areas such as diabetes and asthma appear to work well.
5 Difficult	Increasingly problems with renal transplant patients eg. cyclosporin and epo. GPs also increasingly reluctant to prescribe GnRH analogues for prostate cancer.
6 Further comments	True shared care in some instances is very difficult to achieve with respect to prescribing. Frequently what you are talking about is TRANSFER of responsibility to GP as opposed to shared responsibility. The whole area of shared care seems to have become caught up in the "core - non core" political debate.

Survey Number	43
4 Successful	Process involved in setting up guidelines to be tested by audit. Not yet done (!)
5 Difficult	
6 Further comments	Through good communication setting up of guidelines developed so far has worked well with hard work.

Survey Number	44
4 Successful	In all areas where guidelines are in place they have been welcomed from primary and secondary care.
5 Difficult	Difficulty with fundholding practices in transfer of prescribing due to lack of understanding on their part of what is and what is not agreed.
6 Further comments	

Survey Number	45
4 Successful	Very few implemented successfully.
5 Difficult	Most
6 Further comments	It's a political fudge to resolve a mismatch of resources.

Survey Number	46
4 Successful	For whom? It is really difficult to answer this properly (phone). [Very complex issue. Shared care means different things to different people. Looking cynically it has been quite a success for the hospitals instead of truly sharing care what happens is that the hospital consultant decides what should be prescribed and asks the GP to prescribe it. This is an unsubltle form of cost shifting. We have about six shared care guidelines based around conditions such as diabetes, asthma, hypertension where the aim is to make sure everyone is doing the same thing. As it makes sense that they should be. This ensured that patients are receiving equitable care. The hospital doctors and GPs can then follow the guideline and know where they stand and who is responsible for what.]
5 Difficult	All of it!
6 Further comments	Seen by GPs and consultants as aiding cost shifting of prescribing.

Survey Number	47
4 Successful	
5 Difficult	
6 Further comments	

Survey Number	48
4 Successful	We have some shared care protocols and we have a pilot running in which the GP drugs budget has been top-sliced and money is given to the consultants to provide drugs which should be consultant prescribed. (Copy of guideline attached - *but wasn't!*)
5 Difficult	Getting agreement from the consultants to run the pilot.
6 Further comments	

Survey Number	49
4 Successful	
5 Difficult	Cost shifting to primary care. Poor communications. Lack of acceptance that GPs hold responsibility for prescribing. Issues of core/non-core services for GPs.
6 Further comments	Need to overcome medicolegal responsibility. ?how? Use resources (ie more resources) to support best clinical practice ie usually consultant prescribing. This is an area of interest for our HA -re virement. Please ring for further info. [Virement project giong on. Intention was to do a large project but this has been scaled down due to lack of funding to two practices running a pilot project. The aim is to make sure that the prescribing is done in the most appropraite place. If a GP feels that he does not have the clinical knowledge necessary to take on prescribing a high cost drug the Trust prescribes it and invoices the GP fund holder. This system has been used for

	erythropoietin and growth hormone which are both on the high cost drugs list so they are funded but there is a six month delay before budgets can be reconciled.]
Survey Number	50
4 Successful	EPO, cyclosporin, goserelin
5 Difficult	Growth hormone, IVF, Thalidomide
6 Further comments	I am not convinced that it is working. It remains a cost-shifting exercise and fails to resolve the medico-legal problems with GP prescribing.
Survey Number	51
4 Successful	
5 Difficult	New drugs prescribed in secondary care and patient discharged without discussion between GP and consultant. Appears consultant gives no thought to shared care guidelines and effect on patient/GP until asked by HA.
6 Further comments	
Survey Number	52
4 Successful	Only get to know when there are problems!
5 Difficult	Hospital doctors do not always communicate adequately and in an appropriate time scale with the GPs. GPs contact me complaining that the first they sometimes hear of a patient on these high cost drugs is when the patient requests a supply or in a brief letter from the hospital asking them to prescribe. Shared care in the true sense is often not really shared and often problematic.
6 Further comments	Shared care guidelines are not always followed even when they exist. Shared care should be on an individual patient basis and on individual communication made between the secondary care doctor involved. The patient should not be told that a GP will prescribe unless the GP has already made an agreement to do so. Adequate patient specific information must be made available to the GPs to enable safe prescribing and monitoring - not just a data sheet copy! Shared care must be seen as being in the best interest of patients and not a cost shifting exercise - as so often is the case.
Survey Number	54
4 Successful	
5 Difficult	
6 Further comments	Most of the drugs mentioned here come from tertiary centres and the consultant from the centre discusses sharing the care directly with the GP concerned. There are some regionally prepared guidelines available. HA does not really get involved.
Survey Number	55
4 Successful	
5 Difficult	Getting the concept accepted particularly by Trust consultants. Getting agreement across HA (three acute Trusts).
6 Further comments	

Survey Number	56
4 Successful	Regional protocols currently in use. Development of specific committee agreed 7/97 first meeting is in September 97.
5 Difficult	Riluzole not agreed by LMC
6 Further comments	

Survey Number	59
4 Successful	
5 Difficult	
6 Further comments	

Survey Number	60
4 Successful	Very few, except now have our act together about new drugs.
5 Difficult	Tertiary centres cause the problems most, especially communication on issues about prescribing responsibility. It doesn't really work.
6 Further comments	We have guidance for GPs about how to accept shared care.

Survey Number	61
4 Successful	new in post cannot comment
5 Difficult	new in post cannot comment
6 Further comments	

Survey Number	62
4 Successful	Can't comment - at very early stage of development.
5 Difficult	Can't comment - at very early stage of development.
6 Further comments	

Survey Number	63
4 Successful	epo
5 Difficult	alpha interferon for hepatitis C. Infertility (too many providers - lack of policy especially re private IVF).
6 Further comments	We would like to move towards TRUE shared care (not simply shifting the costs to GPs). Shared care will have prescribing in the most appropriate place for the patient and the therapy.

Survey Number	64
4 Successful	Alpha/beta interferon, protocols have been written, prescribing is by a named consultant at the hospital and the service is managed by Caremark who deliver to patient's homes. This is therefore a home-based service and was the first service of this sort to be set up.
5 Difficult	Treatment of cystic fibrosis as many of the antibiotics used are outside of licensed doses. We are looking to see if we can move prescribing back into secondary care (the funding for this will also move).
6 Further comments	Much of the work of the therapeutics committee is aimed at the managed entry of new drugs. Shared care may or may not be appropriate depending on individual cases. We as a HA will support a GP who does not wish to take prescribing and therefore medicolegal responsibility, if he feels he has insufficient clinical expertise to do so.

Survey Number	65
4 Successful	epo, cyclosporin, riluzole
5 Difficult	clinical responsibility, communication between Trust and GP, financial arrangement
6 Further comments	

Survey Number	66
4 Successful	Managed entry of drugs.
5 Difficult	Compliance of Trusts and consultants and use of guidelines.
6 Further comments	

Survey Number	67
4 Successful	Too early to evaluate
5 Difficult	Inconsistency among GPs about what prescribing they will accept. Inconsistency amongst Trusts about what drugs they wish to pass to primary care. Poor communication between GPs and consultants and vice versa.
6 Further comments	

Survey Number	68
4 Successful	
5 Difficult	
6 Further comments	I feel the whole issue of "shared care" needs to be revisited. I feel the term is being misused for written protocols which give a safety net for consultants when transferring patients back to GPs with a request to prescribe. My interpretation of shared care is an agreement between a consultant, a GP and a patient as to the most appropriate place for them to receive certain aspects of their care. On the whole this isn't achieved by "shared care protocols".

Survey Number	69
4 Successful	The development of arrangements for use of beta interferon in MS seemed to be quite successful.
5 Difficult	Prescribing issues in mental health currently proving to be difficult. General reluctance to take on shared care for certain groups of mentally ill patients following publication of GMSC paper "Mentally Disordered People: Continuing Care in the Community". Fertility issues cause general problems because of the difficulty of private services.
6 Further comments	General impression that hospitals (particularly tertiary centres) have not developed their views on shared care. Still there is a view that GPs will automatically take on the prescribing for all drugs regardless of the clinical responsibility issues. Good evidence for this is provided in Rob Hornes work "Audit of shared care arrangements" done by the University of Brighton.

Survey Number	70
4 Successful	asthma guidelines development (so far)
5 Difficult	1. Where it is motivated solely by drug price. 2. Defining what each share is, not just what is shared. 3. Evaluation
6 Further comments	Motivation should, to my mind, be increased compliance with good practice. It often isn't. Where it is, the investment in audit is usually missing, and data to check is absent.
Survey Number	71
4 Successful	
5 Difficult	
6 Further comments	
Survey Number	72
4 Successful	
5 Difficult	Examples where difficulties arise usually relate to where prescribing is called "shared care" but is more to do with cost-shifting eg IVF, enteral feeds
6 Further comments	
Survey Number	73
4 Successful	Borderline issues, enteral nutrition. (Hoped it would fit into the HTHH package of care but didn't). Agreement between GPs and local providers reached. Some GPs still not happy. Education issue as increase in secondary care use of enteral feeding especially post-stroke and GPs have not kept up with the advances.
5 Difficult	
6 Further comments	
Survey Number	74
4 Successful	Difficult to say!
5 Difficult	Money!!
6 Further comments	When is it shared care? When is it cost-shifting?
Survey Number	75
4 Successful	
5 Difficult	First "hurdle"- assessment of effectiveness and cost effectiveness - insufficient data - time consuming. Response of Trusts when shared care status is denied.
6 Further comments	
Survey Number	76
4 Successful	
5 Difficult	Reimbursement arrangement for GPs who take on the prescribing of particularly expensive drugs. We have a contingency fund to try and reimburse 100% of "high cost drugs" but this cannot be guaranteed at the time when GPs need to decide whether or not to prescribe.
6 Further comments	Many of the GPs still feel it is "cost-shifting" from the hospitals

Survey Number	77
4 Successful	Erythropoetin, Growth Hormone
5 Difficult	Where hospitals/consultants in different HA.
6 Further comment	

Survey Number	80
4 Successful	Second line rheumatology drugs - good communication.
5 Difficult	EPO now becoming hospital only, others may follow?
6 Further comments	

Survey Number	82
4 Successful	beta-interferon
5 Difficult	all others
6 Further comments	

Survey Number	81
4 Successful	erythropoetin
5 Difficult	clozapine
6 Further comments	May become more meaningful when unified budgets are in place.

Survey Number	84
4 Successful	
5 Difficult	ALL -Trusts find it difficult to manage variation in GP's willingness to accept clinical responsibility for prescribing specialist drugs.
6 Further comments	

Survey Number	85
4 Successful	
5 Difficult	
6 Further comments	not applicable

Survey Number	86
4 Successful	Not been in post long enough to know!
5 Difficult	Not been in post long enough to know!
6 Further comments	Shared Care tends to be provider led. More involvement of primary care and greater emphasis on disease management may make shared care more effective.

Survey Number	87
4 Successful	Many GPs have been happy to extend their knowledge and participate to a greater extent in their patients care, good working relationships have been formed.
5 Difficult	Clinical responsibility. Financial difficulties ie inability to vire money from one budget to another. Medicolegal issues - prescribing responsibilities. Patients being "removed" from GP lists once their care has become too expensive or difficult. Many consultants seem to think that GPs should just do what they are told - this only damages the enthusiasm of those GPs who wish to participate.
6 Further comments	I think that "shared care" is really only a delaying tactic to facing up to the rationing debate. In MANY cases there would not be an argument

	about shared care if the drugs were inexpensive. It is an elaborate and time consuming way of trying to equip GPs to take on roles which hospital prescribers would continue to carry out, if only they had the money.
Survey Number	88
4 Successful	
5 Difficult	
6 Further comments	At the HA we do not really believe in the term "shared care" as regards guidelines or rules - we encourage dialogue between GPs and clinicians directly.
Survey Number	89
4 Successful	Restricting therapy to appropriate patients. Ensuring that therapy is available for appropriate patients. Ensuring that therapy is monitored.
5 Difficult	Providing funding for secondary care.
6 Further comments	
Survey Number	90
4 Successful	Diabetes
5 Difficult	
6 Further comments	We have agreed guidelines with Trusts and specialists on several drugs but not shared care ie specialist will prescribe only. Need to define what you think shared care is to get an accurate response.
Survey Number	93
4 Successful	Very few - still largely an exercise of cost-shifting on part of Trusts.
5 Difficult	View of hospital consultant of "why should we have to discuss/agree this with GPs in advance. We just tell them and they should prescribe it"!!!
6 Further comments	Unlikely to work properly until all funding from same pot.
Survey Number	96
4 Successful	See question 1. Process/decision on primary/secondary a little arbitrary
5 Difficult	Top slicing primary care budget to transfer EPO to secondary care. Who do you top slice - and for how long into the future
6 Further comments	
Survey Number	97
4 Successful	
5 Difficult	I was surprised that clozapine had been agreed. A number of GPs have been unhappy to take on prescribing usually for financial reasons. We are finding it difficult to get the consultant rheumatologists to produce tight shared care guidelines.
6 Further comments	This questionnaire is not very well designed. many of the drugs overleaf have been discussed to decide whether they are shared care and decisions have been made to keep them in tertiary care. This is not asked. You do not know from your results whether the drugs have been discussed- perhaps you are not interested - I'm not sure.

Survey Number	98
4 Successful	
5 Difficult	
6 Further comments	We have no formal shared care guidelines however informal ones are often set up - current view is flexibility is good.

Survey Number	99
4 Successful	
5 Difficult	
6 Further comments	Whole section not applicable as no shared care guidelines.

Survey Number	100
4 Successful	Usually better communication. GPs are reimbursed through contingency reserve if drug is high cost and shared care prescribing has been agreed.
5 Difficult	Shared care being used as a route primarily for cost shifting. Judgement as to whether to prescribe should be up to the individual GP based on clinical parameters though consultants sometimes exert pressure on GPs to prescribe when the GP is not happy to accept responsibility.
6 Further comments	

Survey Number	101
4 Successful	The process of developing agreed approaches to disease management between specialists and generalists (both GPs and non-specialist consultants) has opened communications between these groups on many fronts. It has provided a useful cornerstone to developing the input of professionals into Trust and HA management.
5 Difficult	Trying to develop shared care around one drug - too focused and often 'sides' develop with entrenched (usually financial) positions. Also the development of shared care which is very strongly led by secondary care (and usually GPs see no need for shared care) - the shifting of care from secondary to primary care sectors is not an appropriate basis for the development of "shared care"!!
6 Further comments	We don't view it as a 'separate' entity but as part of an evidence based approach to commissioning, then allowing care to be delivered in the most appropriate clinical circumstances, which are in addition convenient to the patient.

Survey Number	102
4 Successful	
5 Difficult	Agreeing contingency guidance for situations where GPs legitimately refuse to share care on the grounds of inadequate clinical knowledge or experience.
6 Further comments	

Survey Number	103
4 Successful	GPs do take on the prescribing of "specialist" drugs but not with a formal shared care protocol.
5 Difficult	Getting the consultants to write one!
6 Further comments	

Survey Number	104
4 Successful	Management of Hep C and the clinical responsibility and thus appropriate funding for: Riluzole, Dornase alpha, alpha and beta Interferon ie the high tech drugs.
5 Difficult	1. Arrangement of funding through contracts. Still an issue for Trusts cost-shifting to GPs even though a policy has been drawn up. 2. Ensuring that all of the parties are aware of the shared care ie communication
6 Further comments	

Survey Number	105
4 Successful	See list.
5 Difficult	Arrangements with tertiary centres.
6 Further comments	

Survey Number	106
4 Successful	
5 Difficult	Transfer to secondary care of clinical and prescribing responsibility.
6 Further comments	Tends not to be shared at all! Simply moving costs to primary care.

Survey Number	107
4 Successful	Where clinical responsibility either defined or funded as secondary care, or where there are agreed shared care arrangements - few problems.
5 Difficult	Some difficulty shifting back clinical responsibility for immunosuppresants, particularly cyclosporin in organ transplantation. Tertiary centre reluctant because multiple purchasers.
6 Further comments	We take a simplistic view that clinical responsibility either sits comfortably in general practice or it doesn't - in which case the consultant should retain clinical and prescribing responsibility. Shared care is resorted to pragmatically where it is in the best interest of the patient convenience.

Survey Number	108
4 Successful	
5 Difficult	Who has clinical and therefore prescribing responsibility. Mainly because this is centres around costs.
6 Further comments	Often seen purely as a cost shifting exercise from secondary to primary care.

Survey Number	109
4 Successful	Collaboration has improved communication and ensured equity of care.
5 Difficult	Getting people to meet let alone try & agree. Trust staff particularly uncooperative.
6 Further comments	Hospital attitude is a serious problem, they do not put forward proposals but try and impose their ideas.

Survey Number	111
4 Successful	
5 Difficult	
6 Further comments	

Survey Number	112
4 Successful	Donepezil - eventually!
5 Difficult	RILUZOLE
6 Further comments	

Survey Number	113
4 Successful	We have managed to separate the issue of shared care from funding. Shared care has been used in the past as cost-shifting. True shared care is necessary for specialist drugs irrespective of whether the GP pays or the HA via contracts.
5 Difficult	Infertility - the HA will only fund one cycle of drug therapy.
6 Further comments	

APPENDIX

6

Coding of Shared Care Data by Hospital Pharmacists

10.30am Wednesday, 11th March 1998
Hospital Pharmacists: Susan Manktelow, Duncan Cripps, Victoria Bendall

Politics - *general comment on bureaucracy, rationing, political environment*	
Positive comments	1
Negative comments	3
Medicolegal - *responsibility*	4
Education - *GP provided with information*	5
Principle of Shared Care - *What it means, how it's interpreted*	18
Shared vs Transfer of Care - *any comments on transfer*	6
Comment on generic guidelines - *how to make a shared care protocol*	7
Not used/not successful	6
Early stages - *no data to comment on yet*	4
Audit- *comment on need to evaluate*	3
Patient selection - *who gets what*	2
Framework - *appropriate drug primary care prescribing, needs a protocol, drug selection*	16
Co-operation - *communication debate, time practicalities, HA ⇔HA, primary care ⇔ secondary care, tertiary care - HA, personnel*	
positive	11
negative	34
Money	
general	15
joint	1
transfer funding	7
cost shifting	22

specific drugs/diseases			
positive		**negative**	
TPN	1	ß-interferon	2
EPO	5	cyclosporin	2
EL(95)5	2	EPO	3
ß-interferon	4	GnRH	1
donepezil	1	growth hormone	1
riluzole	2	infertility	4
infertility	1	thalidomide	1
diabetes	2	riluzole	2
asthma	1	α interferon	1
cyclosporin	1	cystic fibrosis	1
GnRH analogues	1	mental health	2
α interferon	1	enteral nutrition	1
enteral nutrition	1	clozapine	1
growth hormone	1	rheumatogy	1
second line rheumatology	1	high cost	1
dornase α	1	general	2
low cost	1		
general	3		

APPENDIX

7

Coding Shared Care Data Health Authority Questionnaire by Health Authority Staff 5/5/98

	successful	difficult	further comments
joint approach GPs, Trusts, HAs	5	7	
negative comments		11	5
positive comments		1	1
infrastructure/process	9	4	1
negative comment	2	2	1
specific drug	17	13	1
informal agreement	1		1
negative comment		2	1
positive comment		1	
specific disease area	7	9	1
informal agreement	1		
managed entry of drugs	3	2	1
positive comment			1
uncertain	2		
qualitative improvements (communication, collaboration, relationships, wider knowledge, involvement) positive comments negative comments	8 1	10 5	4 2 1
cost	see table 2		
definition of shared care		2	9
usage/implementation	1	2	
positive comments	1		
negative comments	1	2	4
evidence based practice		3	2
clinical responsibility positive comment	2	13	9 1
non-drug payment		5	1
contracting	1	1	
patient's convenience positive comments negative comments		 1 1	6
tertiary referrals		14	2

Coding of Heath Authority Questionnaire Shared Care Data
Dartington 21/4/98

COST			
	successful	difficult	further comments
cost shifting	4	16	11
cost (total)	1	7	2
cost irrelevant	1	0	1
cost effectiveness	0	1	0
null	1	0	1

COST SUBDIVIDED		
	Solution	
Successful		
cost shifting	contingencies/top-slicing implemented null	3 1
cost (total)	null	1
cost irrelevant	shared care implemented	1
null	shared care implemented	1
	total	7
Difficult		
cost shifting	null unified budget suggested contingencies/top slicing implemened shared care implemented	12 1 2 2
cost (total)	null	7
cost effectiveness	null	1
	total	24
Further Comments		
cost shifting	null shared care ..... shared care implemented unified budget suggested	6 1 3 1
cost (total)	null	2
cost irrelevant	null	1
null	unified budget	1
	total	15
Total comments re cost		47

APPENDIX

8

Meeting with finance staff. Thursday 9th July 1998.

Steve Wallwork
Denise Stansfield
Brian Jones

Successful

- collaboration/liaison/communication
- clear guidance framework
- financial (cheap)
- no comment/unsure
- specific drugs
- negative comments
- managed entry of new drugs
- education

Difficult

- poor communication
- finance
- evidence/outside license
- poor collaboration
- difficulty establishing guidelines etc
- lack of clear guidelines
- specific drug
- increased paperwork?
- Lack of leadership
- no comments
- too difficult (individual difficulties not specified)
- tertiary centre
- failure to obey guidelines
- evaluation/audit
- lack of education/knowledge/training
- reluctance to accept responsibility

APPENDIX

9

Direct line: 01752 272588
E-mail: jill.loader@phnt.swest.nhs.uk

2nd December 1998

Dear Colleague

re Shared Care and Hi-tech Health Care at Home Survey

Thank you for your response to my questionnaire survey on the subject of shared care arrangements under EL(91)127 and hi-tech health care at home provided under EL(95)5 distributed last year. I received an outstanding 87% response rate from Health Authorities in England.

I have pleasure in enclosing the summary of findings from the survey that you requested. I have presented some of the findings of the survey at the NPC Conference in Hinckley and as a poster at the BPC Conference in Eastbourne this year [1].

Further surveys of general practitioners, regarding shared care, and Trusts and commercial home care providers, on the subject of hi-tech health care at home, have been completed. The data from these will be synthesised with those obtained from this survey to elucidate a broader picture of shared care and hi-tech health care at home initiatives in England. I hope to publish this in a relevant journal in the near future.

Thanks again for your help in completing the questionnaire.

Your sincerely

Jill Loader
Research Pharmacist

cc Professor Graham Sewell

1. Loader, J. and G.J. Sewell, *The Current Position in England Concerning Home-based Ambulatory Infusion Provided Under EL(95)5.* Pharmaceutical Journal, 1998. 261 (Pharmacy Practice Research Supplement): p. R42.

Summary of Findings of Health Authority Shared Care and Hi-tech Health Care at Home Survey

Jill Loader, Research Pharmacist, Plymouth Hospitals NHS Trust & Post Graduate Medical School, University of Plymouth

Aims and Objectives

The main aim of the survey was to find out the current situation in England regarding the development of shared care guidelines under EL(91)127 and the purchasing and provision of hi-tech health care at home under EL(95)5 from a Health Authority perspective.

The objectives were to find out, for shared care

- which areas have managed to develop and implement shared care guidelines
- for which drugs/diseases
- who is involved with drawing up and agreeing the guidelines
- which aspects of shared care have been successful and which aspects have been difficult or unsuccessful

and for HTHH

- to what extent patients are being treated in their homes with 'hi-tech' therapies
- which drugs are being used and for which conditions
- who is currently providing the various aspects of their care
- which aspects of HTHH have been successful and which have been difficult or problematic

Method

- A questionnaire was designed using recognised questionnaire design techniques.
- Piloted in South and West region and design modified based on comments from the pilot.
- Distributed at Regional meetings of Pharmaceutical (and Medical) Advisers to the 100 Health Authorities (HAs) in England.
- Non-responders followed up by telephone after 6 weeks and 10 weeks.
- The responses were recorded on a database to enable subsequent analysis of the results
- Qualitative data were coded independently by a group of health authority staff, a group of hospital pharmacists and a group of trust finance staff.

Results

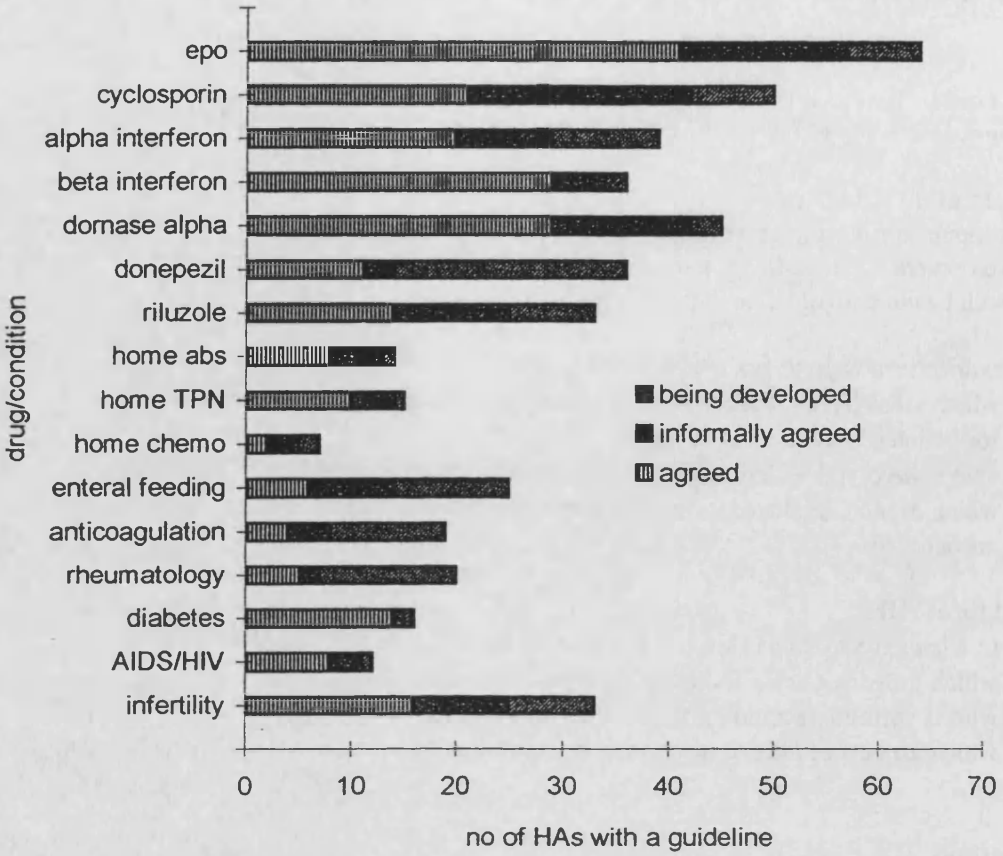
87 of the 100 HAs in England responded to the survey.

Shared Care

81/87 (93.1%) had some kind of guideline for sharing care between primary and secondary care, this included some HAs who had generic guidance and others that had drug or disease specific guidelines.

Figure 1 shows the number of HAs with a guideline for the drugs/conditions specified on the questionnaire. Erythropoietin was the most common subject of a guideline with 74.7% (65/87) of the HAs having a guideline formally agreed (41), informally agreed (17) or being developed (7). Other subjects of guidelines included growth hormone, psychiatric disorders and GnRHs.

Figure 1, Number Of HAs With Shared Care Guidelines For Various Drugs/Conditions



The mean number of guidelines per Health Authority at any stage of development was six. These were agreed and implemented by a variety of committees but mostly by a Health Authority Prescribing Committee (52). Ten HAs reported that there was a specific shared care committee. Representation on these committees was reasonably standard with most including GPs, Trust doctors and pharmacists and Health Authority Public Health doctors , Medical Advisers and Pharmaceutical Advisers as a minimum.

Comments regarding which aspects of shared care had been successful included those regarding a specific drug or disease state, improved communication/collaboration between primary, secondary care and the HAs, the fact that there was a framework/infrastructure around sharing care, benefits with respect to the managed entry of new drugs and education of GPs.

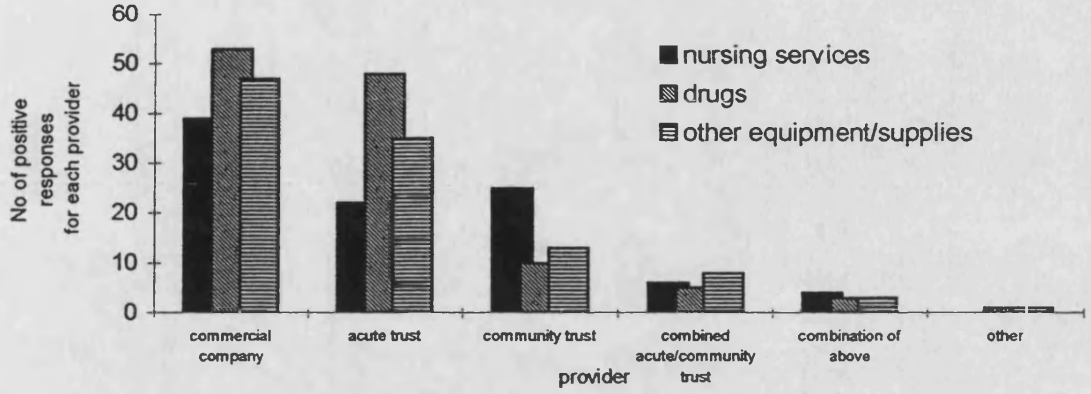
Aspects which had been difficult or problematic included the perception of cost shifting and funding in general, problems with specific drugs, clinical responsibility issues, problems when tertiary providers initiate therapy and communication/collaboration problems.

Hi-tech Health Care at Home (HTHH)

27 out of 87 (31%) were unable to answer any questions regarding the number of patients under their jurisdiction receiving hi-tech health care at home or provide information on the cost of their treatment.

The percentage of HAs treating one or more patients with the following home therapies were TPN 54%, antibiotics for cystic fibrosis 46%, desferrioxamine 25%, antivirals for HIV 10% and chemotherapy 5%. Other hi-tech therapies being given at home included terbutaline for asthma, immunoglobulins, enzyme replacement for Gaucher's Disease and prostacyclin. Commercial home care companies and acute Trusts were found to be the main providers of all aspects of HTHH (Figure 2).

Figure 2, Provision Of Services To Patients Receiving Hi-tech Health Care at Home



Only 17 out of 87 (19%) HAs had any future plans for the care of these patients and none of the HAs knew of any fundholding GP who directly purchased HTHH for their patients.

Comments regarding the aspects of HTHH that had been successful included the fact that the HA has been able to shift the responsibility for contracting for HTHH on to the Hospital Trusts who some see as being better placed to contract for these services and that the contracting process enabled them to achieve better quality of care or cost effective care for the patients.

Difficulties included problems with the initial implementation of EL(95)5, funding of new patients, as there are no new monies available, problems with tertiary centres and extra-contractual referrals, and not knowing whose responsibility the monitoring, audit and evaluation of the service is.

Other comments centred around discussion of cost shifting, clinical responsibility issues, defining shared care and convenience for the patient.

Discussion

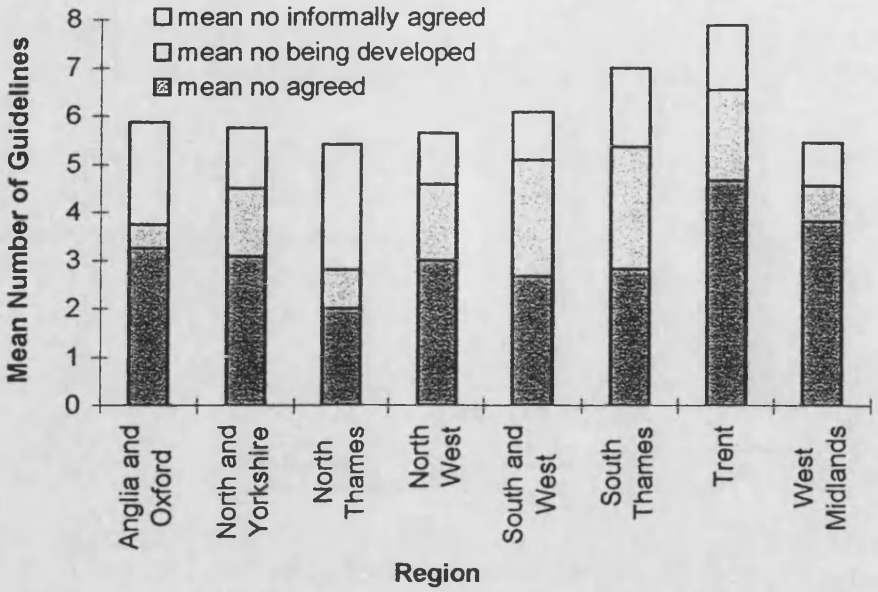
Shared Care

The development of shared care initiatives have been slow throughout England. It can be seen from Figure 3 that there are not large variations throughout the eight regions on the number of guidelines in use. Various committees have responsibility for agreeing and implementing the guidelines but in the main they are Health Authority led and representation on the committees is similar throughout the country.

Shared care guidelines have mostly been developed for high cost drugs such as erythropoietin and cyclosporin. They have been successful in improving communication between primary and secondary care and have put in place an infrastructure for sharing care and for the managed entry of new drugs in some parts of the country. The implementation of shared care guidelines has perhaps been slowed by perceptions of cost shifting and transfer of work load

into primary care. GP concerns regarding clinical responsibility may become the main barrier once Primary Care Groups have developed to a level where a unified prescribing budget is a reality.

Figure 3, Number of Shared Care Guidelines by Region



Hi-tech Health Care at Home

This survey has highlighted the complexity of the current contracting procedure for hi-tech health care at home under EL(95)5. Some Health Authorities have invited tenders to provide the service, whilst others have either continued with arrangements in place before EL(95)5 or passed on the responsibility to the local Trusts. From these data it appears that commercial home care companies have the largest share of the home care market in England closely followed by NHS Trusts. District nurses working for community Trusts are caring for patients receiving HTHH in some areas of the country. Intravenous antibiotics for cystic fibrosis and home TPN are the major infusions being provided in the domicillary setting. It is unclear who is monitoring the quality of service received by patients or patient outcomes.

The large number of HAs that were unable to answer any questions regarding patients under their jurisdiction being treated with hi-tech infusions in their homes is of concern given that the HAs were the bodies charged under EL(95)5 with the responsibility for purchasing "packages of care" for these patients. This might however be a limitation of the survey in that the questionnaire may not have been targeted at or passed on to the correct person within the Health Authority. The absence of monitoring of contracts or patient outcomes, highlighted by the qualitative data is worrying as this could result in poor patient care.

In order to establish the full picture regarding HTHH in England it is necessary to obtain information, not just from the purchasers but also from all providers of "hi-tech" home care, ie commercial home care companies and Trusts. This is the subject of further work of this project.

APPENDIX

10

What would you like a shared care guideline for?

CNS		
Psychiatric drugs	2	
antipsychotics	31	
lithium	3	
dementia	4	
behaviour and learning disabilities	1	
methylphenidate	11	
new Parkinson's drugs	5	
new anticonvulsants	1	
Hormonal		
fertility treatments	11	
endocrine diseases/hormonal treatments	3	
growth hormone	2	
thyroxine	1	
GnRHAs	4	
antiandrogens	1	
Rheumatology		
antirheumatoid drugs	14	
DMARDS	9	
methotrexate	8	
azathioprine	3	
sulphasalazine	2	
penicillamine	2	
hydroxychloroquine	1	
gold	5	
cyclosporin	10	
immunosuppressants	3	
steroids in RA	2	
Impotence		
including MUSE, Caverject and Viagra	7	
Renal and transplant	2	see also cyclosporin and
epo	5	immunosuppressants.
tacrolimus	2	
Drug and alcohol abuse	5	
methadone	5	
acamprosate	1	
Cancer		
chemotherapy	9	see also methotrexate, azathioprine,
octreotide	1	immunosuppressants, antiandrogens,
myeloprolofierative diseases	1	GnRHAs
Other		

amiodarone	2
anticoagulation	1
interferon	4
respiratory disease	1
roaccutane	1
antibiotics	1
parenteral feeds	1
PEG feeds	3
supplemental feeds	1
new cardiac drugs	1

What drugs/diseases would you most like to have a shared care guideline for?

Other comments

Drugs usually initiated in secondary care of which GPs have little experience	8
New drugs	7
Expensive/high cost drugs	7
None/don't want any more	6
Drugs which need monitoring	3
No views/don't know	3
Already covered/happy with what's available	3
Complex drugs	3
Drugs with multiple side effects	2
Would rather secondary care prescribed the drugs	2
Yes	2
Should have individual one for each patient	1
GP's should not prescribe drugs that they do not fully know	1

APPENDIX

11

GP Comments re Shared Care

survey no	**1**
further comments	Transfer of workload including shared care guidelines should be properly funded. Local agreement in place = guideline->LMC/HA negotiating committee->price for work if money available can be purchased. LMC Neg Comm Member!!
survey no	**13**
further comments	transferring - most care is primary care
survey no	**19**
further comments	It would be most convenient to have an A5 sized sheet attached to the specialist letter giving the guideline which would be kept in that patient's notes - rather than yet more paperwork needing yet more filing on yet more shelves that need to be put up somewhere etc etc
survey no	**27**
further comments	regret no time to complete this
survey no	**47**
further comments	This is cost-shifting with no shifting of funds from secondary care into the primary care prescribing budget. We are personally critisised by consultants if we do not prescribe all these drugs when asked by consultants, our drug budget will be overspent and we will have to cut back in other areas.
survey no	**61**
further comments	shared care is never going to work happily until there is a shared prescribing budget!
survey no	**62**
further comments	It isn't just the prescribing it's the associated unwanted workload.
survey no	**64**
further comments	Excellent innovation - shared care guidelines. Redress primary/secondary budget tensions are other areas yet to crack however!

survey no	**65**
further comments	v nice questionnaire, simple, easy and clear
survey no	**70**
further comments	We sometimes seek opinion of Health Authority Pharmacy Department Advisers ie Dr Shivaun Gammie
survey no	**73**
further comments	I remain unhappy about prescribing specialist drugs which I am unfamiliar with. We do not have enough patients on the drugs to become competent with their use. The guidelines may be the way forward. I will find out when I use them.
survey no	**79**
further comments	should not be about cost shifting
survey no	**81**
further comments	The shared care guidelines should be available in electronic form - else they are far too cumbersome!
survey no	**87**
further comments	Any guideline should be 1. very concise if thought essential 2. not talk down to primary care team 3. refer to existing information sources eg BNF & Martindale 4. clearly define the primary care role desired by specialists 5. not be a means of transferring costs from hospital to primary care budgets 6. not be a way of making the primary care team soley responsible medicolegally.
survey no	**112**
further comments	Shared care is about much more than prescribing drugs. Guidelines are seen as a way of getting GPs to write prescriptions for specialists.
survey no	**129**
further comments	Shared care seems an under the counter way of shifting costs from hospital trusts to primary care.

survey no	**134**
further comments	Shared care guidelines sometimes seem like a convenient excuse for GPs not to prescribe perfectly reasonable drugs suggested by secondary care (who have no budget to prescribe them on an ongoing basis, nor the appointment time for pointless follow-ups).
survey no	**137**
further comments	No thanks.
survey no	**143**
further comments	Shared care involves an increasing workload for primary care which is unresourced.
survey no	**147**
further comments	No
survey no	**150**
further comments	I suspect the guidelines are so long and turgid that few primary and even fewer secondary care doctors will refer to them regularly.
survey no	**158**
further comments	It's about transferring costs not care. To date it seems to have been a cost shifting exercise - not just for drug costs but the follow up bloods etc. We pay our staff from our own pockets to the tune of 30%. Consultants don't. Time to stop the budget boundaries I think. Also the psychiatrists are sending patients out on risperidone with no prior contact to GPs and no follow up at all!
survey no	**189**
further comments	Sorry too busy.
survey no	**212**
further comments	unsuitable -presumably
survey no	**242**
further comments	'make' would be a better word than empower. I sincerely hope you don't intend to fill that folder!

survey no	248
further comments	Due to pressure of work Dr xxxxx is no longer completing questionnaires.
survey no	271
further comments	Danger of cost-shifting from secondary to primary care without transfer of resources is that secondary care will continue to be underfunded - effectively subsidised by primary care funds, and that primary care funds will continue to be eroded putting more pressure on primary care budgets. If cost shifts are identified they usually only consider drug costs and ignore costs incurred by extra GP workload & nurse/phlebotomy/pathology handling results/dealing with problems or side effects etc. Is it any wonder primary care is becoming more stressful!
survey no	276
further comments	Note the consultant who has issued a consultant only drug (very expensive too) is still refusing to prescribe it himself (taking no notice of the guideline) - quite awkward for me.
survey no	277
further comments	Monitoring of drugs is not simple in general practice - it can be time consuming monitoring side effects.
survey no	286
further comments	Good communication with hospital doctors over individual patients is more effective than bits of paper gathering dust on a shelf (or in the bin).
survey no	339
further comments	no
survey no	349
further comments	Guidelines are long and repetitive. Punchy, short bulletin point cards would be easier to use.
survey no	362
further comments	More work for GP. Shifting cost to GP. More responsibility. More chance of litigation.

survey no	**365**
further comments	"Integrated care pathways" is the current buzz word, isn't it? Isn't it all just bollocks? We're haggling over whose budget it goes on involving incalculable committee time which has a finite cost and comes out of the various NHS budgets when, in they end, there is an overall health budget. This is a silly Tory game which just keeps getting sillier.
survey no	**376**
further comments	I am not confident about prescribing these medications and will, as much as possible, defer to the relevant consultant about interactions with the patient's other medication. I need the consultant to overview it; ie I am not happy about shared care and will avoid it as much as possible.
survey no	**167**
further comments	Methylphenidate - the patients are being seen regularly in secondary care and I see little point in the GP issuing the prescriptions, as we do not control the dosage/other therapies. EPO - again, the patients are being monitored in secondary care, and I see little point in devolving to the GP apart from cost transfer. 2nd line antirheumatics I see a much stronger case for monitoring and prescribing being undertaken in primary care, due to chronicity of prescribing, lack of resource in secondary care, and the number of patients taking these agents. Anticoagulation - seems entirely appropriate to be monitored in primary care.
survey no	**53**
further comments	Needs to be on a case by case basis and excessive burden of detailed paperwork is not appropriate. We are responsible for correctly prescribing and monitoring as recommended only.
survey no	**215**
further comments	empower GP's to prescribe more complex medication - I hope not!
survey no	**216**
further comments	It is for me not an important issue that of taking the responsibility of prescribing. I think that cost is a driving factor (previously it did not mind).

survey no	256
further comments	Sorry I am burnt out with questionnaires! I must get back to the patients.
survey no	355
further comments	Generally if a consultant recommends a treatment I prescribe that treatment whether or not I have experience in using that drug, for example, I have a liver transplant patient on tacrolimus - the tertiary care centre in London do not provide the regular presciptions for this, I do. I understand that signing the prescription is my responsibility but the monitoring of the doses and the disease is not. I think there is generally still great confusion regarding the GPs responsibility for prescribing "specialist" drugs. If the GP INITIATES a specialist drug the responsibility for the monitoring/ further legal ramifications is clearly the GPs - but I do not think that this should be the case if the consultant recommends the drug in the first place. Unless the consultant is happy to develove responsibility I feel that the consultant should retain responsibility once he/she has prescribed the drug.
survey no	244
further comments	Shared care can become NO care with the patient a political pawn in the middle. Shared care is seen as a means of transferring work from secondary to primary care and the cost thereof.
survey no	15
further comments	cost shifting "inevitable" It is useful as it helps to keep one updated about new treatments and best care for patients.
survey no	359
further comments	Transferring "dumping". Going on for years - "if you mean the activities of the committee". I wonder what you really think has changed. It is unlikely that this issue will ever be resolved, and given the small amount that it represents in the total budget of little significance other than medicolegal. I would rather see responsibility retained by the initiating prescriber. Let's have a sea change in the wway we purchase and supply drugs!

survey no	**185**
further comments	Unfortunately the current guidelines came out too late for some of the drugs that I had already started to prescribe (after being initiated by consultants) eg risperidone, olanzapine, Ritalin, Neoral
survey no	**289**
further comments	no
survey no	**50**
further comments	Shared care working group are under pressure to get it into primary care. I do not see any reason why the hospital cannot prescribe the drugs concerned either on a yellow script (I can't remember it's code) or through repeat dispensing through the hospital pharmacy - but then of course the hospital would have to pay for it!! and that's the whole point - it's all about buck passing and budget shifting.
survey no	**121**
further comments	Most times I am asked to prescribe by the hospital without proper notification or literature on the drug in question.
survey no	**182**
further comments	Shared care often means being placed in a situation of emotional blackmail by hospital to prescribe drugs you are not happy to prescribe, but the implication is if you don't prescribe the patient will not get the treatment. All letters say that helping out is only 1 or 2 patients a month but from every speciality this placea an increasing amount of work on GPs who are already working flat out and we cannot ration care by having waiting lists unlike our hospital colleagues. More work for GPs should produce more income to employ more GPs nurses to provide more appointments. GPs can not take on more and more work to help reduce hospital waiting lists.
survey no	**234**
further comments	Haven't I done one of these before?

survey no	**270**
further comments	It is important that consultants abide by shared care guidelines and that consultants out of area abide by OUR shared care guidelines - this is NOT happening at present. If there is a gap between consultant care and GP care that must be budgeted - and primarily from the secondary care side until communication and agreement has been reached.
survey no	**49**
further comments	Each time we have new guidelines this increases the amount of specialist knowlegde a GP is expected to hold. Where will it end. Will we do away with secondary care routine follow-ups?
survey no	**206**
further comments	At present consultants still recommend drugs to be prescribed with no regard for shared care protocol.
survey no	**321**
further comments	The issue of shared care is not just about clinical responsibility. There is a significant cost in terms of doctor, nurse and admin time associated with treatement currently this cost is NOTbeing met by the Health Authority.
survey no	**44**
further comments	My brain is too exhausted to cope with all this. Sorry.
survey no	**166**
further comments	transferring care and responsibility and cost. cost shifting and work load shifting. Would like more hospital care and more shared care NOT a generalised shift of responsibility, cost and workload.
survey no	**105**
further comments	One often feels normally pressurised into prescribing by hospital and/or patient. The PRESCRIBER has the legal responsibility even if hospital recommended.
survey no	**304**
further comments	I am on the Shared Care Guidleines Committee.
survey no	**52**
further comments	I didn't sign up to shared care protocols.

survey no	**159**
further comments	Touch repetitive on the wording, ? more concise
survey no	**36**
further comments	Not completed as I have already completed one and returned it.

APPENDIX

12

Direct line: 01752 272588
E-mail: jill.loader@phnt.swest.nhs.uk

18th November 1998

Dear Colleague

re General Practice Shared Care Survey

Thank you for your response to my questionnaire survey on the subject of shared care arrangements under EL(91)127, sent out in May this year. I received an outstanding 59% response rate from the General Practitioners in South and West Devon.

All of the comments you sent in have been anonymised and fed back to the South and West Devon, Cornwall and Isles of Scilly Shared Care Working Group.

I have pleasure in enclosing the summary of findings from the survey that you requested.

Thanks again for you help.

Your sincerely

Jill Loader
Research Pharmacist

enc General Practice Shared Care Survey - Summary of Findings

GP Shared Care Survey - Summary of Findings

Objectives
Survey of all GPs in South and West Devon to:

- establish if the local procedure for the development of guidelines is successful
- establish whether the guidelines being produced locally are what the GPs want
- find out the opinions of local GPs on the "concept" of shared care

Method
- Designed questionnaire using recognised questionnaire design techniques.
- Piloted on 5 GPs and modified design based on comments from pilot.
- Distributed by post with a stamped addressed envelope to all 371 GPs in South &West Devon.
- Second mailing sent eight weeks after first.
- Qualitative comments coded by a group with an understanding of the issues involved.

Results
After 2 mailings 18th May 1998 and 13th July 1998 received 218/371 back (59%).

86.7% of respondents had seen a shared care guideline (SCG) produced by the South and West Devon, Cornwall and Isles of Scilly Shared Care Working Group.
46.8% of respondents had used one or more of the guidelines.

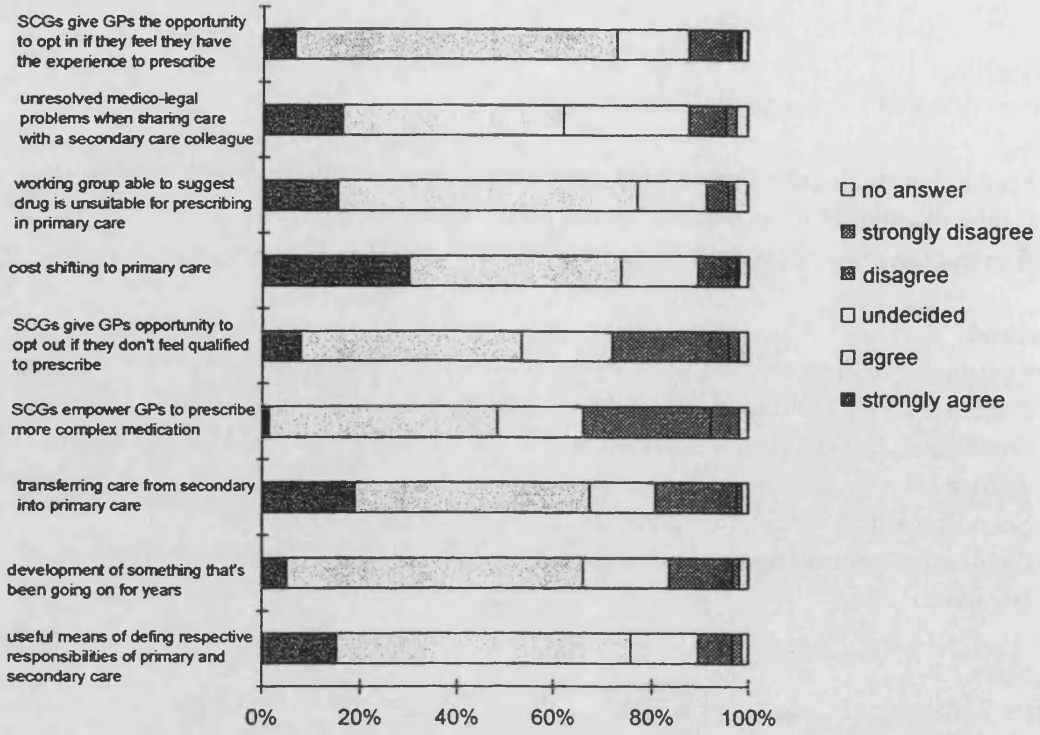
The guidelines were considered to be of some use or very useful by 99.1% of the GPs who answered the question. Most thought the complexity and length were "about right" but 19% of those who answered thought the guidelines were too complex and 29% thought they were too long.

If asked to prescribe a drug of which you had little experience by a secondary care colleague 96 respondents said they would prescribe it if a shared care guideline was available, 91 would prescribe it if they had a recommendation from the hospital in writing and 77 would prescribe it if the request was accompanied by sufficient clinical information. 38 would prescribe it and 36 would ask the hospital consultant to prescribe it. 24 would prescribe if the patient would have difficulties obtaining supplies otherwise and 22 if it was not too expensive.

The drugs and conditions that most GPs said they would like a guideline for were: antipsychotics*, drugs used in rheumatology*, methylphenidate*, fertility treatments, cyclosporin*, chemotherapy, methotrexate*, drugs used to treat impotence, drugs used in the treatment of drug and alcohol abuse and gold*.

**SCGs are available for risperidone, cyclosporin, methylphenidate, penicillamine, gold and sulphasalazine. They will shortly be available for olanzapine, methotrexate and hydroxychloroquine.*

The views of the GPs on the concept of shared care are shown in the graph.



Further comments included concerns over responsibility transfer from secondary to primary care (16), unresourced workload shift (9) and no organised mechanism for transfer of funding for the drugs (10). There were also some negative comments regarding the concept of shared care generally (9).

Discussion

The local procedure for developing SCGs appears to be successful. Most GPs in South and West Devon have seen a guideline and nearly half of the respondents had used one. The guidelines produced so far are generally considered useful and about the right complexity and length. Six of the top 10 requests GPs had for guidelines have been worked on by the group and will shortly be available to local GPs. The respondents are happiest to prescribe a drug of which they have little clinical experience if a SCG is available.

The views of GPs on the concept of shared care were diverse. More GPs felt that SCGs give them the opportunity to opt in to sharing the care of a patient for whom they do feel qualified to prescribe (159) than to opt out if they do not feel qualified to prescribe (116). The largest number of GPs agreed with the statement that the working group is able to suggest that a drug is unsuitable for prescribing in primary care and the largest number disagreed that SCGs empower them to prescribe more complex medication. The statement that the most strongly agreed with was that shared care is about cost shifting to primary care. Concerns about the shift of workload, responsibility and cost came through from further comments made by the respondents.

Thank you very much for your help in completing the questionnaire.

APPENDIX

13

CONFIDENTIAL Survey number ☐☐☐☐☐

Hi-tech Health Care at Home Questionnaire

This questionnaire will take approximately 15 minutes to complete. If you do not know the answer to a question just leave it blank and go on to the next one. If there is somone that I can contact who might know any missing answers please give a contact name and telephone number.

To complete the questionnaire please write in the boxes provided, delete yes or no as required or tick the appropriate box. If you feel an answer might need an explanation, please feel free to add additional comments.

Thank you

1. Do you have the facility for aseptic reconstitution and filling of ambulatory infusion devices in your pharmacy department? *(delete as appropriate)* **yes/no**

If yes, do you have an MCA "Specials" licence? *(delete as appropriate)* **yes/no**

2. Is your pharmacy department involved with the treatment of patients with hi-tech health care at home covered by EL(95)5? *(delete as appropriate)* **yes/no**

If no, who would provide the care for patients in the table listed overleaf?

Thank you for your help, your answer is an important part of this survey, please post the questionnaire back to me in the envelope provided.

3. If the answer to (2) was yes, please complete the table for each of the following groups of patients. (There may be more than one answer to each question)	current number of patients (approx)	approx annual expenditure (to the nearest £25K)	where do patients receive their drug therapy?	who administers the therapy?	who is responsible for training the patient?
			eg. as an outpatient in hospital, at home, gp surgery,	*eg. patient/ relative, hospital outreach nurse, district nurse practice nurse commercial homecare nurse hospital nurse other, please specify*	*eg. hospital nurse, hospital pharmacist, hospital doctor, outreach nurse, commercial homecare company*
.cystic fibrosis atients receiving ıtravenous ntibiotics					
.cancer/haematology atients receiving ıtravenous hemotherapy agents					
. HIV patients ceiving intravenous nti-infectives					
adults receiving tal parenteral utrition					
children receiving tal parenteral utrition					
thallassaemic atients receiving sferrioxamine					
patients receiving a ntinuous infusion anticoagulant eatment					
other, please ecify					

who provides the drugs?	who provides the nursing care?	who provides a 24 hour helpline?	who provides consumable supplies?
eg. hospital pharmacy, community pharmacy, commercial homecare company	*eg. district nurse, hospital outreach nurse, commercial homecare company, hospital nurse*	*eg. on-call hospital doctors, on-call hospital nursing staff, on-call hospital pharmacists, commercial homecare company,primary care team*	*eg. hospital pharmacy, commercial homecare company*

4. Which aspects of hi-tech health care at home have pharmacists in your Trust been involved with?

role	very involved	some involvement	no involvement (please state who is responsible)
CONTRACTING			
• setting-up the hi-tech health care at home program	❑	❑	❑.....
• costing the program	❑	❑	❑.....
• market analysis	❑	❑	❑.....
• contracting for hi-tech health care at home	❑	❑	❑.....
• setting service specifications	❑	❑	❑.....
CO-ORDINATION AND COMMUNICATION			
• co-ordinating the home care program	❑	❑	❑.....
• with other pharmacists eg in nutrition team	❑	❑	❑.....
• with other health care professionals	❑	❑	❑.....
• with a commercial home care company	❑	❑	❑.....
• with patients and their families	❑	❑	❑.....
• patient referral for inclusion in the home care program	❑	❑	❑.....
• patient selection	❑	❑	❑.....
EDUCATION			
• design of written information for the patient on home infusion therapy	❑	❑	❑.....
• educaton/training of patients and their carers	❑	❑	❑.....
• education/training of other health care staff	❑	❑	❑.....
• competancy assessment of patient/carer	❑	❑	❑.....
SUPPLY			
• supply of drugs eg antibiotics, heparin etc	❑	❑	❑.....
• aseptic reconstitution of drugs, TPN and filling of infusion devices, syringes	❑	❑	❑.....
• selection of appropriate infusion pump	❑	❑	❑.....
• maintenance of infusion pumps	❑	❑	❑.....
• providing other items such as infusion pumps, fridges etc	❑	❑	❑.....

role	very involved	some involvement	no involvement (please state who is responsible)
QUALITY ASSURANCE			
• quality assurance of home infusion program	❑	❑	❑.....
• ensuring compliance with service specifications	❑	❑	❑.....
• ensuring compliance with appropriate regulations, guidelines, GMP etc	❑	❑	❑.....
• quality assurance of infusion pumps	❑	❑	❑.....
CLINICAL			
• pharmaceutical advice to prescriber	❑	❑	❑.....
• choice of appropriate drug therapy	❑	❑	❑.....
• selection of venous access device	❑	❑	❑.....
• providing formulation and stability data	❑	❑	❑.....
• documentation of pharmaceutical care plan	❑	❑	❑.....
• maintenance of prescription records	❑	❑	❑.....
• clinical monitoring of the patient	❑	❑	❑.....
• interpretation of laboratory tests	❑	❑	❑.....
• monitoring of patient compliance/adherence	❑	❑	❑.....
• providing a 24 hour help line	❑	❑	❑.....
other roles of the pharmacist in hi-tech health care at home *(please specify)*	❑	❑	❑.....

5. Do any patients outside the scope of EL(95)5 receive home infusional therapy? *(delete as appropriate)*

   If yes, for which drugs/conditions?

6. Are the patients listed in the table in question 3

fully funded by monies from EL(95)5 ☐

or is their care funded by the Trust/provider unit? ☐

Further comments regarding funding

7. Why was your current home care provider chosen to provide care for this group of patients?

quality of their service	☐	financially attractive	☐
convenience	☐	no available alternative	☐
patient acceptability	☐	other, please specify	☐

8. Do you have any guidelines for sharing the care of these patients between primary and secondary care? **yes/no**

If yes, please give details

9. Is there any audit system in place to measure the quality of care received by these patients and patient outcomes? **yes/no**

If yes, who specifies audit criteria and monitors patient outcomes?

health authority	☐	commercial home care company	☐
trust/provider unit	☐	other, please specify	☐

10. In which group of patients has home infusion therapy worked best and why?

11. What are/have been the barriers in providing infusion therapy at home in your area?

12. What is the major reason that your Trust provides hi-tech health care at home? *(please tick the appropriate box)*

- to improve patient independence/quality of life ❑
- to reduce treatment costs ❑
- to free-up hospital beds/outpatient beds ❑
- other, please specify ❑

13. Is there any collaboration between the Trust and the Health Authority Prescribing Team eg pharmaceutical adviser on issues regarding hi-tech health care at home? **yes/no**
If yes, please specify

14. What, in your opinion, is the general level of awareness of hi-tech health care at home in your hospital amongst

	low	moderate	high	don't know
• nurses	❑	❑	❑	❑
• pharmacists	❑	❑	❑	❑
• doctors	❑	❑	❑	❑

Any other comments you would like to make or explanations of your answers?

Your name and address (if you would like to give it)

Job Title

Name of Trust

Please tick if you would like a summary of the results obtained from this questionnaire ☐

Thank you for completing this questionnaire.

Please post it back to me even if you have been unable to complete all of the questionnaire!

Please return in the stamped addressed envelope to:
Jill Loader, Pharmacy Office, Mount Gould Hospital, Mount Gould Road, Plymouth, PL4 7QD. ☎01752-272588

APPENDIX

14

Plymouth Postgraduate Medical School

Pharmacy
Level 05
Derriford Hospital
Plymouth
Devon PL6 8DH
United Kingdom

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Dr Graham Sewell
Reader in Biomedical Sciences

Tel 01752 272588
1st November 1997

Dear Colleague,

Thank you for agreeing to complete this questionnaire. Your time is greatly appreciated.

As discussed on the telephone, I am a pharmacist working in Plymouth and am researching the current position in the United Kingdom on 'hi-tech healthcare at home' under EL(95)5. The work is for a M.Phil. project registered with the University of Plymouth, under the supervision of Dr Graham Sewell, Reader in Biomedical Sciences. The project is sponsored by a "Developments in the Organisation of Care Project Grant" from the NHS Executive.

EL(95)5 instructed Health Authorities to make provision through their contracts to support patients at home whose treatments included the delivery of drugs together with other products and equipment needed to administer them, typically provided as packages of care, such as TPN, intravenous antibiotics and chemotherapy. Prescribing of these services by general practitioners was stopped from 1st April 1995.

My aims are to find out

- how many Trusts are providing home infusional therapy and for how many patients
- which drugs are being used and for which conditions
- who is providing the drugs, supplies and nursing care
- why the above where chosen to provide the care
- whether there are audit systems in place to measure the quality of patient care received by these patients and patient outcomes
- what are the barriers to providing home infusional therapy
- in which patients has home therapy worked best and why
- what is the role of the hospital pharmacist in the provision of hi-tech health care at home

The information I obtain will be used with that obtained from similar questionnaires to Health Authorities and commercial home care organisations to establish the current position in the UK with regard to home infusional therapy. I intend to publish an analysis of the information I obtain in a relevant health care journal. The data will be combined so that the data from individual Trusts will not be identifiable. I will be happy to send responders a summary of my findings.

Please fill out the questionnaire even if you contract with a third party to provide services for these patients. If you do not feel that you are the most appropriate person to complete this questionnaire please pass it on to someone who may be able to help.

Many thanks in advance for your help.

Yours faithfully

Jill Loader.

Jill LOADER (Miss), Research Pharmacist

THE QUEEN'S ANNIVERSARY PRIZES
FOR HIGHER AND FURTHER EDUCATION
1994

CONFIDENTIAL Survey number ☐☐☐☐☐

Hi-tech Health Care at Home Questionnaire

This questionnaire will take approximately 20 minutes to complete. If you do not know the answer to a question just leave it blank and go on to the next one. If there is someone that I can contact who might know any missing answers please give a contact name and telephone number.

To complete the questionnaire please write in the boxes provided, delete yes or no as required or tick the appropriate box. If you feel an answer might need an explanation, please feel free to add additional comments.

Thank you

Thank you for your help, your answer is an important part of this survey, please post the questionnaire back to me in the envelope provided to:
Jill Loader, Research Pharmacist, Pharmacy Department,
Derriford Hospital, Plymouth, PL6 8DH. ☎01752-272588

Question 1 ☺*(It's OK it gets easier after this!!)*

Please answer the following questions for the groups of patients under the care of your Trust treated with hi-tech health care at home. (There may be more than one answer to each question).

	cystic fibrosis patients receiving intravenous antibiotics	**cancer/ haematology patients receiving intravenous chemotherapy agents**	**HIV patients receiving intravenous anti-infectives**
1. Current number of patients *(approx)*			
2. Where do patient receive their drug therapy? *eg as outpatient, at home*			
3. Who administers the therapy? *eg patient, hospital outreach nurse, district nurse, nurse from commercial company*			
4. Who is responsible for training the patient? *eg hospital nurse, hospital pharmacist, commercial company*			
5. Who provides the drugs? *eg hospital pharmacy, community pharmacy, commercial home care company*			
6. Who provides the nursing care? *eg district nurse, hospital outreach nurse, commercial home care company, hospital nurse*			
7. Who provides equipment and supplies? *eg. hospital pharmacy, commercial home care company*			
8. Who provides a 24 hour helpline? *eg on-call hospital doctors, pharmacists, nusres, commercial home care company, primary care team*			
9. <u>Approx</u> annual expenditure for total package of care for all patients in this group *(to the nearest £10K)*			

NB. If you only supply part of this service please specify which part and give the cost.

	adults receiving total parenteral nutrition	children receiving total parenteral nutrition	thallassaemic patients receiving desferrioxamine	patients receiving a continuous infusion of anticoagulant treatment	other, please specify
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					

Question 2
Which aspects of hi-tech health care at home have pharmacists in your Trust been involved with?

role	very involved	some involvement	no involvement (please state who is responsible)
CONTRACTING			
• setting-up the hi-tech health care at home program	❑	❑	❑.....
• market analysis	❑	❑	❑.....
• contracting for hi-tech health care at home	❑	❑	❑.....
• setting service specifications	❑	❑	❑.....
CO-ORDINATION AND COMMUNICATION			
• co-ordinating the home care program	❑	❑	❑.....
• with other pharmacists eg in nutrition team	❑	❑	❑.....
• with other health care professionals	❑	❑	❑.....
• with a commercial home care company	❑	❑	❑.....
• with patients and their families	❑	❑	❑.....
• patient selection	❑	❑	❑.....
EDUCATION			
• design of written information for the patient on home infusion therapy	❑	❑	❑.....
• education/training of patients and their carers	❑	❑	❑.....
• education/training of other health care staff	❑	❑	❑.....
• competency assessment of patient/carer	❑	❑	❑.....
SUPPLY			
• supply of drugs eg antibiotics, heparin etc	❑	❑	❑.....
• aseptic reconstitution of drugs, TPN and filling of infusion devices, syringes	❑	❑	❑.....
• selection of appropriate infusion pump	❑	❑	❑.....
• maintenance of infusion pumps	❑	❑	❑.....
QUALITY ASSURANCE			
• quality assurance of home infusion program	❑	❑	❑.....
• ensuring compliance with service specifications	❑	❑	❑.....
• ensuring compliance with appropriate regulations, guidelines, GMP etc	❑	❑	❑.....
• quality assurance of infusion pumps	❑	❑	❑.....

role	very involved	some involvement	no involvement (please state who is responsible)
CLINICAL			
• pharmaceutical advice to prescriber	❑	❑	❑.....
• choice of appropriate drug therapy	❑	❑	❑.....
• selection of venous access device	❑	❑	❑.....
• providing formulation and stability data	❑	❑	❑.....
• documentation of pharmaceutical care plan	❑	❑	❑.....
• maintenance of prescription records	❑	❑	❑.....
• interpretation of laboratory tests	❑	❑	❑.....
• monitoring of patient compliance/adherence	❑	❑	❑.....
• providing a 24 hour help line	❑	❑	❑.....
• other roles of the pharmacist in hi-tech health care at home *(please specify)*	❑	❑	❑.....

Question 3

Do any patients outside the scope of EL(95)5 receive home infusional therapy *eg. apomorphine for Parkinson's Disease*? *(delete as appropriate)* **yes/no**

If yes, for which drugs/conditions?

Question 4

Are there any patients under the care of your Trust who were receiving hi-tech health care at home prior to EL(95)5 and continue to do so as part of a bulk contract e*g chemotherapy*? *(delete as appropriate)* **yes/no**

If yes, please specify

Question 5 ☺*(You're doing really well, nearly finished!)*
Why was your current home care provider chosen to provide care for this group of patients?

quality of their service	❑	financially attractive	❑
convenience	❑	no available alternative	❑
patient acceptability	❑	other, please specify	❑

Question 6
Do you have any guidelines for sharing the care of these patients between primary and secondary care? **yes/no**
If yes, please give details

Question 7
Is there an audit system in place to measure the quality of care received by these patients? **yes/no**

a) If yes, who specifies audit criteria?

health authority	❑
trust/provider unit	❑
commercial home care company	❑
other, please specify	❑

b) Who measures the quality of care received?

health authority	❑
trust/provider unit	❑
commercial home care company	❑
other, please specify	❑

c) How is this measured? Please specify.

Question 8
Is there an audit system in place to measure patient outcomes? **yes/no**

a) If yes, who specifies audit criteria

health authority	❑
trust/provider unit	❑
commercial home care company	❑
other, please specify	❑

b) Who monitors patient outcomes?

health authority	❑
trust/provider unit	❑
commercial home care company	❑
other, please specify	❑

c) How is this achieved? Please specify.

Question 9
In which group of patients has home infusion therapy worked best and why?

Question 10
What are/have been the barriers in providing infusion therapy at home in your area?

Question 11
What is the major reason that your Trust provides hi-tech health care at home? *(please tick the appropriate box)*

- to improve patient independence/quality of life ❑
- to reduce treatment costs ❑
- to free-up hospital beds/outpatient beds ❑
- other, please specify ❑

Question 12
Is there any collaboration between the Trust and the Health Authority Prescribing Team (eg pharmaceutical adviser) on issues regarding hi-tech health care at home? **yes/no**
If yes, please specify

Question 13
What, in your opinion, is the general level of awareness of hi-tech health care at home in your hospital amongst

	low	moderate	high	don't know
• nurses	❑	❑	❑	❑
• pharmacists	❑	❑	❑	❑
• doctors	❑	❑	❑	❑
• trust managers	❑	❑	❑	❑

☺*(You made it!! Congratulations.)*
Any other comments you would like to make or explanations of your answers?

Your name and address (if you would like to give it)

Job Title

Name of Trust

Please tick if you would like a summary of the results obtained from this questionnaire ❑

Thank you for completing this questionnaire.

Please post it back to me even if you have been unable to complete all of the questionnaire!

Please return in the stamped addressed envelope to:
Jill Loader, Pharmacy Department, Derriford Hospital, Plymouth, PL6 8DH. ☎01752-272588

APPENDIX

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Survey no | | | | | |

Trust Telephone Survey

Date 1 Date 2 Date 3

1. Does your Trust have a pharmacy department? **yes/no**

If no, from where does your Trust obtain it's pharmaceutical supplies?

Go to question 5.

2. Do you have the facility for aseptic reconstitution/filling of ambulatory infusion devices in your pharmacy department? **yes/no**

If no, who does this for you?

Go to question 5.

If yes, do you have a technical services manager or equivalent?

Name	
Telephone no	
Address	
Date contacted	

3. Does this unit have an MCA "Specials" licence? **yes/no**

4. Do you have a manufacturing unit that has an MCA "Specials" licence? **yes/no**

Survey no | | | | | |

5. Are there any patients under the care of your Trust treated with hi-tech health care at home in accordance with EL(95)5 eg. antibiotics for cystic fibrosis patients, TPN, HIV, Thallassaemics? **yes/no**

6. Not under EL(95)5 eg ceredase for Gaucher's Syndrome, apomorphine for Parkinson's Disease? **yes/no**

7. Do you ever aseptically reconstitute drugs or fill infusion devices for treatment of patients at home? **yes/no**

8. If yes to 5 or 6 or 7, would you fill out the questionnaire? **yes/no**

Comments
Name
Address
Telephone no
Date sent

APPENDIX

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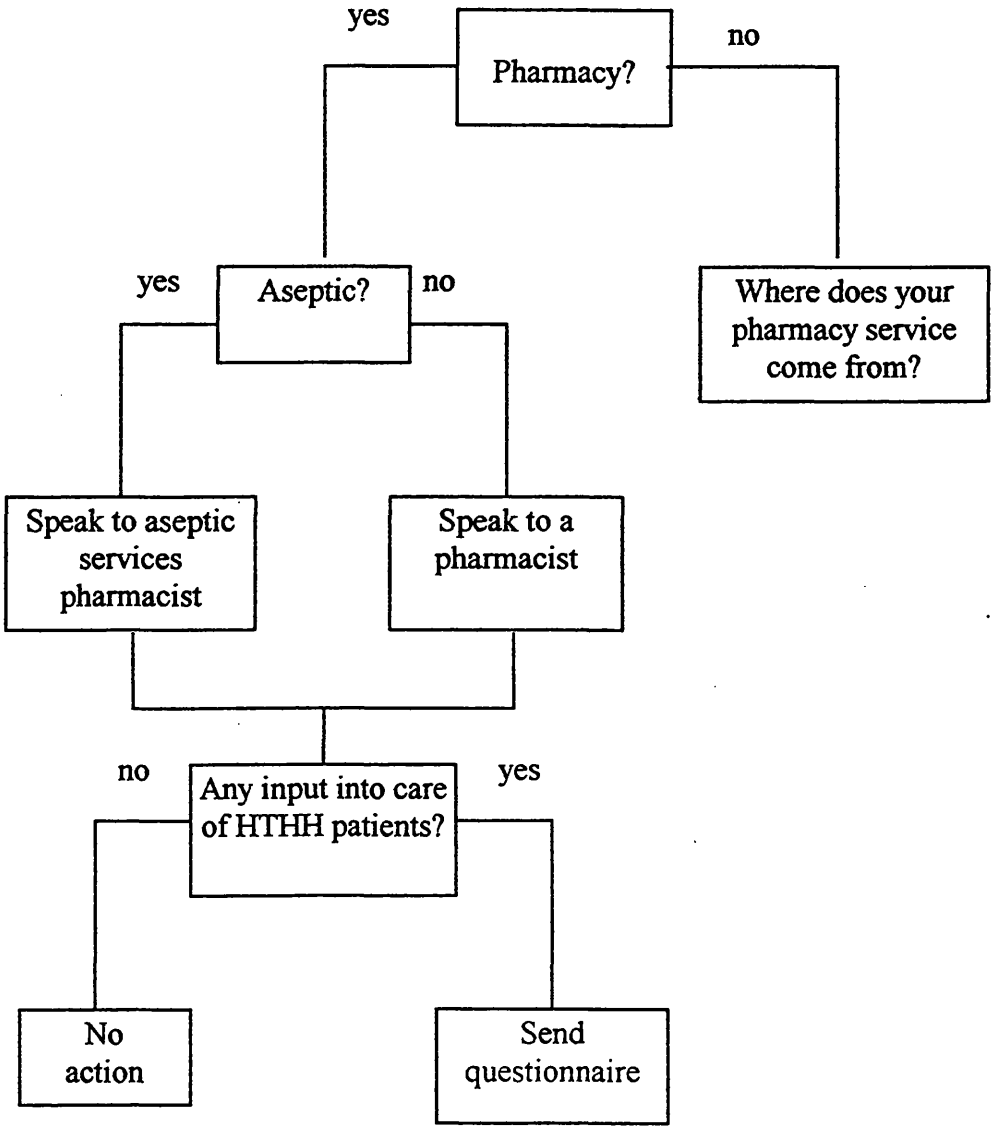
Telephone Survey



APPENDIX

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Direct line: 01752 272588
E-mail: jill.loader@phnt.swest.nhs.uk
30h November 1998

Dear

I am a pharmacist working in Plymouth and am researching the current position in England on 'hi-tech healthcare at home' under EL(95)5 [1]. The work is for a M.Phil. project registered with the University of Plymouth, under the supervision of Graham Sewell, Professor of Pharmacy and Pharmacology. The project is sponsored by a "Developments in the Organisation of Care Project Grant" from the NHS Executive.

I have completed national surveys of Health Authorities and NHS Trusts to establish the current situation in England with regard to the purchasing and provision of "hi-tech" health care at home (HTHH). The aim of this survey of commercial home care providers is to complete the national picture by finding out what is provided and to what sorts of patients by the commercial sector.

The findings of this project will be published in an appropriate scientific journal and may be presented at conferences. The data collected from this survey of commercial home care providers will be synthesised with that collected from Trusts and Health Authorities to gain an understanding of the overall picture regarding the purchasing and provision of HTHH in England. **It should be stressed that no company, Health Authority or Trust will be identified in any publication or presentation of the findings of this project.**

It is hoped that this work will raise the profile of home infusional therapy in England so your help in completing the enclosed survey would be greatly appreciated. If you have any questions regarding the project or completing the questionnaire please do not hesitate to contact me.

Yours sincerely

Jill Loader, Research Pharmacist

1. NHS Executive, *EL(95)5 Purchasing Hi-Tech Health Care for Patients at Home.* Letter, 1995. Leeds.

Survey no

Commercial Home Care Company Survey

EL(95)5 instructed Health Authorities to make provision through their contracts to support patients at home whose treatments included the delivery of drugs together with other products and equipment needed to administer them, typically provided as packages of care, such as TPN, intravenous antibiotics and chemotherapy. Prescribing of these services by general practitioners was stopped from 1st April 1995.

The aim of this survey is to establish the current situation in England regarding the purchasing, provision and monitoring of hi-tech health care at home (HTHH) under EL(95)5. Synthesis of the data collected with that collected from national surveys of Health Authorities and NHS Trusts will enable the current situation with regard to HTHH in England to be elucidated.

No company will be identified in any publication or presentation of the findings of this project.

Thank you for your help.

Please return in the stamped addressed envelope provided to:
Jill Loader, Plymouth Post Graduate Medical School, c/o Pharmacy Department, Derriford Hospital, Plymouth, PL6 8DH

Question 1

Do you provide an entire package of care for patients being treated at home with hi-tech infusions covered under EL(95)5 such as home TPN? *(delete as appropriate)* **yes/no**

If no, do you provide a package of care for these patients jointly with a hospital or other organisation? *(delete as appropriate)* **yes/no**

If no to both please specify what kind of service you provide.

Question 2

What aspects of care does you company provide? *(tick appropriate boxes)*

	company provides	**company subcontracts to provide**	**hospital or other organisation provides**
• Nursing care	☐	☐	☐
• Patient training	☐	☐	☐
• Education of other health care professionals	☐	☐	☐
• Aseptic reconstitution of drugs/filling of infusion devices	☐	☐	☐
• Provision of equipment such as fridges, pumps etc	☐	☐	☐
• Provision of disposables	☐	☐	☐
• Delivery to patient's home	☐	☐	☐
• 24 hour help-line	☐	☐	☐
• Waste disposal	☐	☐	☐
• Maintenance of pumps etc	☐	☐	☐
• Other, please specify	☐	☐	☐

Question 3

Approximately how many treatment doses per day do you supply to patients being treated with home intravenous infusions in **England**?

Under 10 per week ☐
10-30 per week ☐
30-60 per week ☐
60-90 per week ☐
90-120 per week ☐
over 120 ☐

comments

Question 4
Which of the following drugs do you supply? *(please tick)*

	currently provide	have provided in past	have never provided	may provide in the future
1. intravenous antibiotics for cystic fibrosis patients	❐	❐	❐	❐
2. intravenous chemotherapy agents for patients with cancer	❐	❐	❐	❐
3. intravenous anti-infectives for HIV patients	❐	❐	❐	❐
4. total parenteral nutrition (TPN)	❐	❐	❐	❐
5. intravenous desferrioxamine for Thallaesaemics	❐	❐	❐	❐
6. continuous intravenous anticoagulant treatment	❐	❐	❐	❐
7. intravenous antibiotics for other conditions	❐	❐	❐	❐
8. intravenous terbutaline for asthma	❐	❐	❐	❐
9. intravenous prostacyclin	❐	❐	❐	❐
10.intravenous immunoglobulins	❐	❐	❐	❐
11.subcutaneous beta-interferon	❐	❐	❐	❐
12.enzyme replacement for Gaucher's disease	❐	❐	❐	❐
13.intravenous Iloprost	❐	❐	❐	❐
14.intrathecal baclofen (for relief of spasticity as a result of spinal cord disease)	❐	❐	❐	❐
15.intravenous calcium gluconate infusions (for ricketts)	❐	❐	❐	❐
16. methotrexate for arthritis	❐	❐	❐	❐
17.Other, please specify	❐	❐	❐	❐

Question 5
How many Health Authorities/Trusts do you currently have contracts with either for individual patients or for all of the HTHH patients? *(tick appropriate box)*

	Health Authorities	Trusts
1-3	❐	❐
4-7	❐	❐
8-11	❐	❐
12-20	❐	❐
>20	❐	❐

comments

Question 6
When you tender or bid for a contract who specifies service specifications? *(tick as appropriate)*

Health Authority	☐
Trust	☐
Other, please specify	☐

Question 7
Are you aware of any Health Authority or NHS Trust with whom you have a contract having an audit system in place to
(delete as appropriate)

- monitor the service you provide? *(delete as appropriate)* **yes/no**
- measure patient outcomes? *(delete as appropriate)* **yes/no**
- measure your service against the agreed service specifications? *(delete as appropriate)* **yes/no**
- benchmark your service against that of other providers? *(delete as appropriate)* **yes/no**

If yes to any of the above, please give details

If you would not mind being contacted for clarification of your answers please give your name and contact number.

Name .....

Contact number .....

Thank you.

Please return in the stamped addressed envelope provided to: Jill Loader, Plymouth Post Graduate Medical School, c/o Pharmacy Department, Derriford Hospital, Plymouth, PL6 8DH.

APPENDIX

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Health Authority Contracts for HTHH

survey no	bulk	Separate	comments
1	No	Yes	
2	No	No	TPN and intermate separate contract, everything else bulk.
3	No	No	The HA Medical And Prescribing Adviser contract for the service with our local Trust pharmacy department.
5	No	No	separate contract for patients previously being treated through primary care. Trusts contract as part of bulk contract for new patients.
6	Yes	No	We do not contract separately for hi-tech therapy.
16	No	No	unsure
17	No	No	HA contracts with combination of acute trust and commercial home care company
21	No	Yes	Performance management team contract for hthh
23	No	No	CAPD as bulk, others individually.
24	No	No	HA contract
25	Yes	No	
26	No	No	Responsibilityiven to trusts, HA holds budget.
27	No	No	In most cases we have put it back into secondary care as part of a bulk contract with providers. The above patients are provided through Caremark.
29	No	Yes	
30	No	No	
31	No	Yes	Separate contract with secondary or tertiary care provider who usually sub-contract.
32	No	No	
33	No	No	don't know
34	Yes	No	Part of a bulk contract with several providers
35	No	Yes	
36	No	No	
37	Yes	No	Bulk contract with main provider.
38	No	No	
39	No	No	
40	Yes	No	Part of bulk contract with acute provider
41	No	Yes	Up to 97/98 separate contract. Trust answer separate contract by the HA.
42	Yes	No	Because of question 1 this is dealt with as part of a bulk contract should any particular issue arise.
43	No	No	
44	No	Yes	
45	No	No	sub-contracted to provider
46	Yes	No	Bulk, Trust contracts out.
47	No	No	TPN via provider, tube feeds via gp and Caremark
48	No	No	Both - CAPD fluids as part of the contract with Provider Trusts. Drug regimens by a commercial home care company.
49	No	Yes	
50	No	No	Handled by Birmingham consortium very little known in Sandwell.
51	No	Yes	
52	No	No	Part of a consortium contract involving 3 HAs. Block contracts or in contracts with the host speciality hospital
54	Yes	No	For first year HA had separate contract then gave the money to the Trusts who are now responsible for contracting for hi-tech health care at home. Think that three Trusts are doing it themselves.
55	No	No	All Trusts (acute and community) contract directly with providers. Numbers not known.
56	No	No	CAPD fluids via Black Country Consortia - separate contracts for TPN/IV antibiotics as and when required
59	No	Yes	TPN is a separate contract. Intravenous drugs contracted for via sub-

			contracting arrangement with Trusts.
60	No	Yes	As a separate cost per case contract at one of our providers
61	Yes	No	yes
62	No	Yes	Separate contract by HA - the service was tendered.
63	No	No	We have a small Caremark contract but the bulk of EL(95)5 money was for renal dialysis - this was blocked back to the Trust who now contract for supplies. This also happened for HIV drugs.
64	No	Yes	
65	No	No	
66	Yes	No	Bulk contract to provider.
67	No	Yes	Separate contract by HA except CAPD which is done by the Trusts
68	No	No	both
69	No	Yes	
70	No	No	neither, responsibility devolved to main providers of routine care
71	No	No	Provided as part of bulk contract with a provider, except for 3 exceptions, therefore cannot fill above in any detail.
72	Yes	No	
73	No	Yes	Separate contract between HAs and companies involved.
74	No	No	Most of funding is through bulk contracts with some providers, (eg £30K to Community Trust for Hi-tech equipment & feeding). Other individuals are treated with separate contracts direct to the provider (eg Caremark or Derbyshire Ambulance Service).
75	No	No	A contract within a contract
76	Yes	No	Part of the main contract
77	Yes	No	Bulk (I think) (not sure)
80	Yes	No	I assume it is a bulk contract with the provider.
81	Yes	No	
82	Yes	No	bulk contract with provider
84	Yes	No	Incorporated within acute contracts.
85	Yes	No	Part of contrct with provider.
86	No	No	?
87	No	Yes	Forms part of separate contracts.
88	Yes	No	Part of bulk contract now.
89	No	Yes	This patient is still under a separate contract. All others are included in standard Trust contract.
90	Yes	No	
93	No	No	Dealt with individually - some are within block contracts ie cf packages of care, others as ECRs ie Ceredase & TPN
96	No	Yes	
97	No	No	
98	No	No	we contract with Trusts to provide a service - they sub-contract but could do it in house if they wanted to.
99	No	No	
100	No	Yes	
101	No	Yes	Separate contracts with Trusts and suppliers outside the NHS.
102	No	No	For 1998/99 it will be an addendum to bulk contracts - thereafter probably included.
103	No	No	Both
104	No	Yes	Separate contract by our HA
105	No	Yes	
106	No	No	Both - Part of District Contract with Salford Royal Hospitals for TPN; spot purchase for rest.
107	No	Yes	
108	No	Yes	As above -separate contract.
109	No	Yes	
111	No	Yes	HA Caremark
112	No	Yes	

113	No	Yes	

APPENDIX

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HTHH Successful, Difficult and Other Comments

survey no	1
6 successful	Good quality service provided. Healthcare at Home service has improved care of patients previously getting TPN from Caremark.
7 difficult	Budget, PPA didn't transfer enough money. This area is increasing.
8 further comments	

survey no	2
6 successful	
7 difficult	
8 further comments	The main issue is that of sharing the risk, small numbers of patients therefore variation in likely spend.

survey no	3
6 successful	Contracting with our acute Trust has been successful in that they are the specialist unit for cystic fibrosis/TPN etc and have a good working knowledge and good working relationship with us at the HA. Using Trust contract has kept costs down.
7 difficult	Problems have risen around new patients being entered onto the contract, eg whether the patient was suitable for home health care under EL(95)5
8 further comments	

survey no	5
6 successful	no specific issues have arisen
7 difficult	
8 further comments	

survey no	6
6 successful	
7 difficult	
8 further comments	Difficult to answer any of these questions in our circumstance - I assume it has been reasonably successful because the Trust aren't jumping up and down as yet!

survey no	16
6 successful	
7 difficult	
8 further comments	I'm not involved in this at all. There was no GP prescribing for these products and therefore no need to implement the EL as such. Local Trust deals with these patients.

survey no	17
6 successful	
7 difficult	
8 further comments	

survey no	21
6 successful	Passing the responsibility on to others!
7 difficult	No cost control at the moment. Evaluating the service provided by the commercial company.
8 further comments	

survey no	23
6 successful	Renal services.
7 difficult	Immunoglobulins. Original setting up for EL(95)5.
8 further comments	

survey no	24
6 successful	Remained with previous provider - continuity of care for patients.
7 difficult	Not sure we are getting best value for money.
8 further comments	Dilemma - is the hassle of tendering process and possible disruption to patient care worth the possible financial saving?

survey no	25
6 successful	All - now vired money to hospitals for immunoglobulins.
7 difficult	Deciding what is 'hi-tech' health care.
8 further comments	

survey no	26
6 successful	Trust pharmacist negotiates health care at home contract. They know the patients' needs, consultant requests etc. Can arrange knowing individual needs of patients supplier to suit these needs.
7 difficult	Before trust arranged, we were told at the last minute and didn't have time to arrange properly. Also initially contracted with one company and felt they gave poor value for
8 further comments	

survey no	27
6 successful	?cystic fibrosis
7 difficult	Cancer therapies. Moving back to secondary care as recommended in the report "Purchasing Hi-tech Health Care for Patients at Home" by Mark Pilling and Tom Walley, University of Liverpool, Department of Pharmacology and Therapeutics,
8 further comments	The report mentioned in question 7 concluded that 1. formal structures for monitoring contracts need to be introduced at purchaser level 2. that from 1997/98 purchasers should place their contracts with NHS Tertiary centres 3. That the NHS Tertiary centres should have overall responsibility for patients at home ensuring they receive the most appropriate and effective hi-tech health care at home.

survey no	29
6 successful	Two ongoing contracted providers a) Commercial Home Care Company b) tertiary acute trust. One person has care specifically tailored using GPs, local trust and tertiary centre.
7 difficult	
8 further comments	

survey no	30
6 successful	Purchasing direct from the Acute Trust let them develop their service.
7 difficult	Control ie once it became part of contracts doubts arose about double charging and ECR mechanisms.
8 further comments	

survey no	31
6 successful	Local secondary care units have co-ordinated TPN services very well.
7 difficult	Audit of outcomes, quality of service etc.
8 further comments	

survey no	32
6 successful	
7 difficult	
8 further comments	

survey no	33
6 successful	TPN
7 difficult	
8 further comments	

survey no	34
6 successful	
7 difficult	No-one really seems to know much about it but as part of the bulk contract doesn't seem to be any problems. Initially implementation of EL(95)5 was a nightmare.
8 further comments	Sorry I haven't been able to complete the questionnaire very fully.

survey no	35
6 successful	Use of hospital services seems to work well with cf patients and cf nurses (more consultations, visits etc)
7 difficult	
8 further comments	

survey no	36
6 successful	
7 difficult	
8 further comments	

survey no	37
6 successful	- Identification of patients receiving therapy. - Appreciation by HA managers of the problems involved with such patients.
7 difficult	Difficult for provider units to give accurate data (numbers & costs). Ongoing monitoring of budget allocation.
8 further comments	A shambles when first introduced (at national level). Difficult to know which therapies to include/exclude. No extra funding from DoH. Provider units have found other ways to get money from the GP prescribing budget.

survey no	38
6 successful	
7 difficult	
8 further comments	

survey no	39
6 successful	
7 difficult	
8 further comments	

survey no	40
6 successful	Smooth changeover in responsibilities.
7 difficult	Identifying patients in the first place when legislation came in.
8 further comments	

survey no	41
6 successful	Trust answer: Transitions from GPs have been seamless. Discussions with provider Trusts progressing value for money.
7 difficult	Trust answer: Funding new patients.
8 further comments	

survey no	42
6 successful	As mentioned earlier - this was a "non-event" in this HA by and large
7 difficult	
8 further comments	

survey no	43
6 successful	
7 difficult	
8 further comments	The prescribing department deals with data generated from PACT. We therefore have no data on hi-tech health care at home. Please contact Rob Little, Director of Finance, North and East Devon Health Authority regarding this section.

survey no	44
6 successful	Have been much more successful with Caremark than through the Trusts.
7 difficult	
8 further comments	

survey no	45
6 successful	
7 difficult	
8 further comments	

survey no	46
6 successful	CAPD successful.
7 difficult	desferrioxamine, TPN
8 further comments	Caremark seem to have a stranglehold and prices have increased.

survey no	47
6 successful	Works satisfactorily. GP prescribes feeds. Caremark deliver feeds and equipment. Costs of equipment agreed in contract with Community Trust.
7 difficult	
8 further comments	

survey no	48
6 successful	Continuity of care to the patients.
7 difficult	
8 further comments	

survey no	49
6 successful	care of cf patients, looking to develop this service
7 difficult	identifying precise costs, agreeing standards of service and best practice - as in a need to ask provider for "standards".
8 further comments	Introduced at short notice with very limited time to develop and implement.

survey no	50
6 successful	None
7 difficult	Monitoring the service.
8 further comments	

survey no	51
6 successful	TPN formerly supplied by a commercial home care company. Local acute trust has been awarded this service providing good quality service at lower cost.
7 difficult	Continuing financial pressures in CAPD fluid with increasing pool of renal patients.
8 further comments	

survey no	52
6 successful	The consortium approach has been successful - sharing the risk particularly as we are a small authority.
7 difficult	Funding of equipment for enteral feeds. Continuing cost pressures as more 'hi-tech' drugs become available. (Getting information initially - now OK)
8 further comments	The Regional Specialities Consortium will complete this on behalf of the 3 HAs it covers (Birmingham, Sandwell and Solihull). Ours will therefore be included in their reply.

survey no	54
6 successful	
7 difficult	
8 further comments	

survey no	55
6 successful	
7 difficult	
8 further comments	

survey no	56
6 successful	
7 difficult	One home TPN patient threatened to use the whole budget when treatment initiated. Predicting the use of the budget is impossible due to small number/amount of patients with eg. exacerbation of infection in cystic fibrosis and TPN needs.
8 further comments	

survey no	59
6 successful	TPN
7 difficult	Unable to comment.
8 further comments	

survey no	60
6 successful	So few patients it's difficult to assess.
7 difficult	Very few patients coming on.
8 further comments	

survey no	61
6 successful	unsure
7 difficult	
8 further comments	

survey no	62
6 successful	TPN
7 difficult	A child on TPN from Great Ormond Street Hospital, for this patient we haven't been able to contract with the company of our choice.
8 further comments	Tendering for hi-tech health care is a good process to follow. communication with the relevant stakeholders is crucial to the success of such a service.

survey no	63
6 successful	Because of the low volume of demand there have been no problems.
7 difficult	1. Internal problems within HA (FHSA/HA mergers, staff changes etc) have made continuity difficult - even locating the right budget line from one year to the next! 2. The money top sliced from the GP budgets for HIV drugs was relatively low. This was blocked back to the Trust but was insufficient for the demand in 1995/96. This was a
8 further comments	Our view was that it was appropriate in most cases to allocate the EL(95)5 money that was top sliced from the FHSA and given to the HA to the relevant Trusts and allow then to arrange the supply function either in-house or via a home care provider. The pressure to develop hi-tech home care comes from within the Trusts and should be included in their business plans so that appropriate discussions can take place. There are no special

survey no	64
6 successful	interferon alpha/beta- see earlier
7 difficult	
8 further comments	

survey no	65
6 successful	We have directly sub-contracted with our Trust to provide the services to our local patients.
7 difficult	Patients outside of our HA, new patients, potential wastage, audit
8 further comments	

survey no	66
6 successful	Since devolving to the Trust and Home Care Companies there are few problems.
7 difficult	Very few problems.
8 further comments	

survey no	67
6 successful	No patient complaints following contract changes
7 difficult	None
8 further comments	

survey no	68
6 successful	
7 difficult	TPN patients have been a problem when sent out before nutritional requirements were stable enough - in a couple of situations, the Trusts rather than the commercial company have had to act as supplier due to the specific patient requirements.
8 further comments	We have recently moved to Caremark (Fresenius since the take-over) for our beta-interferon patients which, although this comes out of a different budget (ie not EL(95)5), seems to work very well. Our local Trusts are keen to keep as many of the hi-tech responsibilities themselves although the additional services offered by the home care companies seem to make them a more cost-effective option. Having been keen to support the Trust involvement in these areas as we have so few patients - this may

survey no	69
6 successful	A new system was implemented to reduce the delay between Trusts applying for funding and the HA authorising treatment. This has proved very successful in enabling both the HA to keep control of the budget and the Trusts to provide a faster, more effective
7 difficult	There have been no problems with supplying patients with hi-tech health care. There have been some minor inconveniences with attempting to find out from the Trusts how effective certain treatments have been.
8 further comments	Many of the original problems in establishing the current level of service were associated with the inaccuracy of the baseline information provided to HAs to manage the original transfer from FP(10) to HCHS funding. This was coupled with the growth in the use of these types of delivery processes which is increasing at a faster rate than HCHS funding growth. HA felt that they had been given a raw deal in managing the changeover when there were large discrepancies between the transferred funding and the actual spend on

survey no	70
6 successful	Got it off our agenda without effort.
7 difficult	Potential savings for not accrue to us and difficult platform from which to develop it.
8 further comments	1. What was the purpose of EL(95)5 2. Has it been achieved
survey no	71
6 successful	
7 difficult	None to my knowledge.
8 further comments	
survey no	72
6 successful	
7 difficult	Staffing difficulties at acute Trust HAs meant they cannot provide service for community patients in some instances. Often too many people involved in discussing a particular patient eg. Consultant, Trust Managers, several people at the HA leading to delays in
8 further comments	Difficult to find answers to all questions. There seems no single person in the HA with an overview on the subject.
survey no	73
6 successful	TPN - as it is the major aspect of HTHH that concerns the HA, it has been successful. Other aspects of HTHH insignificant.
7 difficult	No particular problems. When EL(95)5 was introduced helped by the commercial companies. Trawled GP PACT catalogue, tracked down individual patients. This was a big job but not a difficulty.
8 further comments	
survey no	74
6 successful	We found that contracting through Trusts was more successful than attempting to contract directly with suppliers. Trusts have closer contact with the patient, more idea of their requirements & better economies of scale for the tendering process. Our role has been to monitor that process. We have obtained standard approx. costs from provider organisations to benchmark and ensure that we are getting a value for money, high quality
7 difficult	Setting up a contract outside of the tertiary provider has proved time-consuming. We had to write up a contract and agree it and then change it as the tertiary provider changed the treatment regime of the patient.
8 further comments	Our ideal model of service would involve the Trusts sub-contracting services for identified individuals on our behalf (see response to question 6). We would like sight of the contract and the tendering process to ensure that it was fair and high quality. We would compare the cost of the service with standard basic costs for that service to ensure value
survey no	75
6 successful	There have been no significant problems.
7 difficult	None.
8 further comments	

survey no	76
6 successful	Trusts are now responsible for the provision of those services who have the expertise and knowledge to provide the best care. This is regarded as a success in itself
7 difficult	None that the HA are aware of.
8 further comments	
survey no	77
6 successful	
7 difficult	
8 further comments	
survey no	80
6 successful	No obvious problems because no communication from Trusts.
7 difficult	Potentially all of it! Who should be monitoring this? Are other areas of the country different with respect to HA monitoring?
8 further comments	
survey no	81
6 successful	
7 difficult	
8 further comments	New patients coming through as ECRs Has been difficult to monitor.
survey no	82
6 successful	
7 difficult	Lack of monitoring. High dependence on commercial company providers.
8 further comments	
survey no	84
6 successful	Savings realised through transfer from commercial 'niche-market' organisations to NHS providers without loss of quality of care.
7 difficult	ALL- particularly where providers have wished to increase patient nos. receiving HTHC eg desferrioxamine
8 further comments	
survey no	85
6 successful	Smooth transition from old arrangements to new arrangements.
7 difficult	Sorting out the funding arrangements. Ensuring providers obtain value for money by putting the contract out to tender.
8 further comments	It is not high on the current agenda at the moment hence the rather vague answers given previously.

survey no	86
6 successful	?
7 difficult	?
8 further comments	

survey no	87
6 successful	
7 difficult	
8 further comments	

survey no	88
6 successful	Reviewing desferral supply change from Caremark -> acute Trusts as providers
7 difficult	Approval of new patients via ECR process - how can these be turned down??
8 further comments	

survey no	89
6 successful	The transfer of responsibility to the Trusts - BUT I don't know what they are doing. So far no complaints but no monitoring in force (to my knowledge).
7 difficult	
8 further comments	

survey no	90
6 successful	
7 difficult	
8 further comments	

survey no	93
6 successful	Specification for services. Moving to local providers.
7 difficult	Being involved early enough.
8 further comments	

survey no	96
6 successful	Contracts seem to work well. Tender exercise earlier this year involved quality specifications (and not the cheapest option)
7 difficult	
8 further comments	

survey no	97
6 successful	
7 difficult	
8 further comments	I'm sorry but the contacting team said that it would take too long to complete.

survey no	98
6 successful	We had no problems during the transfer year and all seems well (with the exception of equipment) now.
7 difficult	When community trusts are involved we sometimes have problems with funding of equipment ie pumps however this is usually due to increased demand rather than ..edness
8 further comments	

survey no	99
6 successful	
7 difficult	
8 further comments	

survey no	100
6 successful	Removing high-tech prescribing away from GPs to the care of specialists responsible for the patient.
7 difficult	Uncertain that we are obtaining the best value for money.
8 further comments	

survey no	101
6 successful	The services are better 'commissioned' than supplied as previously via GP prescription. We have been able to develop specifications for service, know exactly what we have to budget for, and can develop new services as needed (eg. liquid oxygen)
7 difficult	Some difficulties in getting standard service spec agreed between Has, especially for supply from tertiary centres (who obviously cannot meet each and every HAs requirements). The way it was done was very poor (by DoH) and put patients at risk of potential service cessation. Lots of time needed to sort it out initially (and way out of proportion to the importance of HTHH in most advisers workload).
8 further comments	

survey no	102
6 successful	
7 difficult	Devolving the budget, which accounted only for patients currently receiving care by 1 April 1996 in a way that accounts for future use eg TPN costs doubled in one year but not because of policy changes just because 3 more HA residents went on to TPN.
8 further comments	

survey no	103
6 successful	
7 difficult	The fact that the money was top-sliced from GP's budgets and then was lost into the system. There is no money ring-fenced for hi-tech healthcare.
8 further comments	

survey no	104
6 successful	1. Competition - therefore reduction in cost but a more integrated service. 2. GPs no longer prescribing in an area in which they had no clinical responsibility.
7 difficult	
8 further comments	

survey no	105
6 successful	TPN provision, HIV drugs
7 difficult	Grey areas of prescribing eg iv immunoglobulin and iv albumin
8 further comments	

survey no	106
6 successful	undertook recently a tender for TPN with Manchester Children's and Adult Services.
7 difficult	Getting hospital providers to own budget and take responsibility for discharging patients and for the home care arrangements.
8 further comments	

survey no	107
6 successful	Good cost containment through competition. HA holds the budget for those transferred back and has been able to afford additional care such as walk-about oxygen from BOC.
7 difficult	
8 further comments	

survey no	108
6 successful	
7 difficult	Limited number of suppliers. Providers (ie Trusts) can contract with who they like, no responsibility as such to check quality or value for money.
8 further comments	Should have included enteral tube feeding.

survey no	109
6 successful	
7 difficult	Audit, monitoring. Attempts to increase patients receiving care at home was ****ately realised eg for rheumatology.
8 further comments	Apologies for the blanks. PS. Pharmaceutical Adviser deals with hi-tech she is on maternity leave.

survey no	111
6 successful	
7 difficult	
8 further comments	New in post so info difficult to get.

survey no	112
6 successful	Cost reduction for some services
7 difficult	The paper chase and lost expenditure when TPN patients have gone into hospital -waste TPN bags.
8 further comments	

survey no	113
6 successful	Multiple Sclerosis - beta interferon, TPN, cystic fibrosis
7 difficult	Nil
8 further comments	

APPENDIX

20

Coding of Qualitative HTHH Data

Meeting Dartington, 23/10/98 10am
Jane Pyle, Libby Hardy, Chris Roome

Health Authority Questionnaire

1. Finance
   - a unpredictable 12
   - b insufficient 8
   - c benefit/reduction in cost 9

2. Shared Risk/Responsibility 2
   - a better 12
   - b worse 2

3. Tertiary Centre experience/involvement
   - a good 2
   - b bad (causes problems) 5

4. Ignorance/unfamiliarity 14

5. Audit of quality
   - a how do we know value for money 11
   - b patient care 12

6. Patient criteria/ hand over issue
   - a clear 3
   - b unclear 14

7. Comparison with previous service (ie before EL(95)5)
   - a better than before 22
   - b worse than before 2

8. Communication
   - a good 3
   - b bad 4

9. Not blank but haven't made a comment which contributes anything 10

Coding of Qualitative HTHH Data

Meeting Dartington, 23/10/98 10am
Jane Pyle, Libby Hardy, Chris Roome

Trust Questionnaire

1. Finance			
	a	unpredictable	5
	b	insufficient	23
	c	benefit/reduction in cost	0
2. Shared Risk/Responsibility			
	a	better	2
	b	worse	5
3. Tertiary Centre experience/involvement			
	a	good	1
	b	bad (causes problems)	2
4. Ignorance/unfamiliarity			6
5. Audit of quality			
	a	how do we know value for money	0
	b	patient care	0
6. Patient selection/ hand over issue			
	a	clear	2
	b	unclear	11
7. Comparison with previous service (ie before EL(95)5)			
	a	better than before	10
	b	worse than before	2
8. Communication			
	a	good	3
	b	bad	7
9. Not blank but haven't made a comment which contributes anything			29
10.No barriers			4
11. Workload/manpower			
	a	better	0
	b	worse	6
	c	unpredictable	3
12. Geographical barriers			4

13. Provider's service

a	adequate	0
b	inadequate	9

14. Training as barrier 2

What worked best?

A	TPN	22
B	cystic fibrosis	11
C	Cancer	14
D	unspecified group	3
E	HIV	5
F	renal	1
G	heart/lung transplant	1
H	haematology (not cancer)	7
I	respiratory	1
J	rheumatology	1

APPENDIX

21

Triangulation Of Trust Data –Comparison Of Information Obtained In Written Survey And Telephone Survey.

Survey Number Chosen Randomly	Telephone survey	Written Survey	Same person
303	Unlicensed aseptic unit. Have patients on home chemotherapy via Graseby pumps who come in once a week. Buy the syringes from Caremark.	2 cystic fibrosis patients and between 1 and 3 chemotherapy patients, drugs provided for both by hospital pharmacy as dry powders. 10 HIV patients some treated at home some in HIV day case unit CHCC supplies home patients and hospital pharmacy supply patients who come to the day unit.	?
37	Have an aseptic unit. Some haematology patients have ceftazidime made up so that they can go home during the day. No HPN. G-CSF and flushes drawn up, cytarabine syringes so patients come into hospital for one of the doses each day and have the other at home. All have a 24 hour expiry as isolators not in Class D air. Medax bags at end of use.	3 haematology/cancer patients at any one time receiving chemotherapy infusions supplied by hospital pharmacy. No other patients specified.	yes
116	Have an aseptic unit and have applied for a licence. No home TPN patients or antibiotics but occasionally make up chemotherapy in Baxter Intermate infusers for patient to start in the hospital then take home.	2 cystic fibrosis patients supplied by hospital pharmacy dispensary. 4 cancer patients, infusers supplied by company. 1 thalassaemic patient supplied by hospital pharmacy. 1 other- paediatrics receiving antibiotics for eg meningitis once a day administered by outreach nurse and supplied by hospital pharmacy.	yes
96	Aseptic unit do not have a pharmacist who has day to day input. Make up chemotherapy for a couple of patients 5FU, fludarabine etc. looking to take on HTHH. Pharmacist at .....supply with chemo. Will answer the relevenat parts of the questionnaire and pass on to	4 cystic fibrosis patients under joint care organised by ...*(another Trust)*, drugs supplied by Caremark. 0 chemo patients 4 thalassaemic patients supplied by hospital pharmacy.	no
283	Unlicensed aseptic unit. No-one at the moment, have had a number of people in the past TPN, cystic fibrosis antibiotics, HIV ganciclovir, desferral. Have also supplied special insulin dilutions, epidurals for terminal patients and terbutaline infusions.	Cystic fibrosis 0 patients, sometimes 1-3. Chemotherapy 0 patients sometimes as continuation of inpatient treatment. HIV 0 – very occasionally 1. TPN adult 0 – have treated patients for up to 9 months. Other home epidurals occasionally. All supplied by hospital pharmacy.	yes
244	Unlicensed aseptic unit. Have patients on home chemotherapy via Graseby pumps who come in once a week. Buy the syringes in from Caremark.	2 cystic fibrosis patients and 1-3 chemo patients supplied by hospital pharmacy. 10 HIV patients some at home some come to HIV day case unit. Commercial company supply home patients and hospital pharmacy day case unit patients.	?
53	Have an aseptic service. Minimal input, about 1 patient per year who they provide with 1-2 weeks of HPN and supply heparin syringes before the care is taken over by Caremark (Fresenius).	1 chemotherapy patient who receives therapy in outpatients. 1-2 adult HPN patients supplied by hospital pharmacy/commercial home care company.	?
233	Unlicensed aseptic unit. Had 1 TPN patient who died ages ago. Have home antibiotics eg ganciclovir but a commercial company deal with it. haematology patients come to ward to receive drugs.	Chemotherapy occasionally at home but rare provided by hospital. 2 thalassaemics receiving desferrioxamine from hospital pharmacy.	no
118	Licensed aseptic unit. Have 65 home care patients. provide TPN to patients all over the country even in Scotland. Hope in Manchester are the other people who supply a lot of home TPN. BANS survey think register is now held at GOS (or maybe Birmingham Childrens or Hackney Childrens) we used to have it.	65 TPN supplied by commercial home care company.	yes

300	Unlicensed aseptic unit. It is a rare occurrence. Have one patient currently on intermittent courses of cytarabine subcutaneously and he has been taught to give himself twice daily injections for a week repeated roughly every month. Have a patient who has ganciclovir at home, she comes to the hospital once/week and picks up a weeks supply. I think the district nurse goes in and infuses it. Most of the TPN etc is based at Sheffield. Have had HPN in distant past for scleroderma patient.	1 HIV patient supplied by hospital pharmacy. 1 other – Occasional subcutaneous cytotoxic therapy at home, self-administered, supplied by hospital pharmacy.	yes
92	Have a licensed aseptic unit and make up ganciclovir, foscarnet and amphotericin for HIV patients.	12 HIV patients supplied by hospital pharmacy.	?
322	Unlicensed aseptic unit. Have TPN patients at home but we do not make it up ourselves a commercial company does it.	6 cystic fibrosis patients supplied by hospital pharmacy. 4 TPN patients supplied by a commercial company.	yes
271	Unlicensed aseptic unit. Satellite oncology pharmacy, some patients have 24 hour pumps. We have one shared patient with ....*(another Trust)*. We used to sort out the TPN but .....do it now because it got too complex for the doctors and pharmacists here. Have the odd cystic fibrosis patient who does their own antibiotics at home. Do not provide much of a CIVAS service. Will fill in the questionnaire and then pass on to the oncology pharmacist to complete.	20 chemotherapy patients supplied by the hospital pharmacy.	?
258	Pharmacists and technicians counsel patients with pumps for chemotherapy, mostly 5FU. It is dealt with through pharmacy. Oncology. Manufacturing unit make up ganciclovir etc	27 home chemotherapy patients with Walkmed pumps supplied by hospital pharmacy.	yes
178	Unlicensed aseptic unit. Yes do have HTHH patients. 1 home TPN which we make ourselves and 2 which are looked after by Central Homecare. Occasionally have home iv antibiotics which are dealt with by a commercial home care company.	2 children's TPN provided by commercial company. Cannot answer on cystic fibrosis patients with home antibiotics which I know goes on in the hospital but I have no involvement.	?
17	Manager –only have a few patients. We organise the service but subcontract it out to a commercial company. Looked into being a provider as have specials licence for TPN. If had patients may supply the bags. Have supplied Caremark with TPN.	2 cystic fibrosis patients and 1 HIV patient supplied by commercial company or hospital pharmacy. 1 child on HPN organised by GOS. 1 patient on immunoglobulin supplied by commercial home care company.	yes
174	Aseptic unit – unlicensed. Patients who have TPN at home are managed by Hope Hospital in Manchester. Have thalassaemics who are funded from region.	3 chemotherapy patients supplied by hospital pharmacy.	yes
321	Unlicensed aseptic unit working under Section 10 exemption. Have cystic fibrosis patients on antibiotics but currently this is mostly provided by Caremark. Have one domicillary TPN patient under the care of .....*(another Trust)*, feeds come from Caremark and are organised by .....*(another Trust)* Patients on home treatment for CMV we make up their ganciclovir in our cytotoxic suite. 3-4 patients are having adjunct continuous chemotherapy, 5FU. Make up 7 days supply in house. Also do 2-3 days of vincristine and doxorubicin. Have looked at doing the cystic fibrosis antibiotics ourselves but funding issues are a problem.	12 cystic fibrosis patients supplied by commercial company and hospital pharmacy. 0 chemotherapy patients at present supplied usually by hospital pharmacy, no HIV patients currently sometimes receive therapy in outpatients supplied by hospital pharmacy.	yes

APPENDIX

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Telephone survey

Survey No	1	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	Principal Pharmacist, Preparative Services Central Pharmacy. Yes, do have input into hi-tech healthcare at home, will answer questionnaire.						
Survey No	2	*Region*	A&O	*Pharmacy*	☐	*Send questionnaire*	☑
Comments	Pharmacy provided from Ipswich Hospital. Do some antibiotics for cystic fibrosis patients. Sent both survey no 2 & 12 for Ipswich Hospital asking him to pass on the appropriate one. See 12.						
Survey No	3	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	Divided into 2 trusts - Norfolk Mental Health and James Paget Healthcare Trust. James Paget - Have a pharmacy and make up antibiotics for children to use at home. Outreach children's nurse Marion Steward. Senior technician aseptic services Judy Ovenstone. Advised to send questionnaire to David Todd, Director of Pharmacy. Sent with note.						
Survey No	4	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	Pharmacy open part-time. Pharmacist available on bleep through switchboard. As a pharmacy do not have anything to do with the care of these patients but district nurses do provide some services. Oxford Community Trust who share a boarder have developed their service and have good IV trained community nurses to support these patients at home. Pharmaceutical care from acute trust. So sometimes district nurses from this trust asked to help with care of eg iv antibiotics for orthopaedic patients. Will try to answer questionnaire. Have you spoken to Beth Taylor - survey of hospital at home?						
Survey No	7	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	Pharmacy manager. Have 2 HIV patients supply ganciclovir, foscarnet. Will answer questionnaire.						
Survey No	12	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	Sent with 2 as same pharmacy supply both Trusts. Have not spoken to G. Hanson (who looks after aseptic reconstitution), spoke to Chris Galloway who has both 2 & 12.						
Survey No	14	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	One patient on home TPN and one on desferrioxamine. Will answer the questionnaire. (Also provide services for 33) therefore sent her two questionnaires.						
Survey No	15	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	Have recently had one home TPN patient for about a month. Made up the tpn but do not have a civas service. All cf patients come under Papworth. Will answer questionnaire.						
Survey No	17	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	Manager - only have a few patients. We organise the service but subcontract it out to a commercial company. Looked into being a provider as have specials licence for TPN. If had patients may supply the bags. Have supplied Caremark with TPN. Going to China for 3 weeks will complete on return.						
Survey No	25	*Region*	A&O	*Pharmacy*	☑	*Send questionnaire*	☑
Comments	Technical Services Pharmacist. Couple of home TPN, dealt with by Caremark/Fresenius. Occassionally fill CADD pump for chemotherapy but no civas service. Will complete questionnaire.						
Survey No	27	*Region*	A&O	*Pharmacy*	☐	*Send questionnaire*	☑
Comments	No pharmacy but have a pharmacist. Give intravenous antibiotics to patients at home. Have specially trained nurses to put in central lines and community nurses to look after the patients in their homes. The nurses usually go in to the patients home and administer the drug but occasionally a patient is trained to give it themselves. The community nurses work very closely with infection control and microbiology. Don't send patients home to other districts where they can not be monitored. There is a specially allocated ward in the hospital for these patients. Pharmacist attends consultant ward rounds and has clinical input. Initially had large input into the scheme when setting up protocols etc, now leaves it up to the specialist nurses who are very competant. Why don't you come and visit? Yes, I'll fill in the questionnaire.						

Survey No 28 *Region* A&O *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit at the Churchill Hospital. Limited amount of patients. Have done desferrioxamine and do home TPN but service is stopping because the HA are not paying for it. Will answer questionnaire.

Survey No 30 *Region* A&O *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have a contract with Central Homecare to supply these services. Will try and fill in the questionnaire.

Survey No 31 *Region* A&O *Pharmacy* ☑ *Send questionnaire* ☑

Comments Supply 23, do have aseptic suite, supply children with home antibiotics, have a hospital at home scheme. Will fill in questionnaire.

Survey No 36 *Region* A&O *Pharmacy* ☑ *Send questionnaire* ☑

Comments Very small aseptic unit, no licence. Occasionally make items for patients to use at home eg. desferrioxamine pump, cytarabine in CADD pumps as part of 5/10 day regimen, CVADD - doxorubicin, vincristine for 4 days. Will fill in questionnaire

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Survey No 37 *Region* A&O *Pharmacy* ☑ *Send questionnaire* ☑

Comments (spinal injuries etc) Aseptic unit. Some haematology patients have ceftazidime made up so that they can go home during the day. No HPN, gCSF and flushes drawn up, cytarabine syringes so patients come into hospital for one of the doses each day and have the other at home. Al have a 24 hour expiry as isolators not in Class D air. Medax bags at end of use. Will answer questionnaire.

Survey No 40 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Kay Marriot ext 3509. Have had home TPN in past. Do not have many AIDS patients, sometimes IV antibiotics but often given once daily at the hospital in paediatrics. Unit not licenced use Kabimix standard regimen or if patient needs something else try to base on a Pharmacia regimen so that stability OK. Do not make up own formulations.

Survey No 41 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Yes cystic fibrosis patients have home iv antibiotic therapy but everything including the drugs and nursing care comes from Newcastle. Do make up cytotoxics in an unlicenced aseptic unit. Mostly fludarabine and the nurse goes out to the patient's home to give it. Will fill out questionnaire.

Survey No 43 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit at St Luke's Hospital. Make up a weeks worth of antibiotics for cf patients and draw up saline. Technicain will ask John Suddo, Pharmacist to answer questionnaire. In a Warfarin clinic at the moment.

Survey No 45 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic service. 5FU infusions, no HPN, abs for cf, have done a one-off ganciclovir. Will answer questionnaire.

Survey No 46 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic service. Home TPN, Northumberland patients get supplied from Newcastle, RVI with homecare but planning to start a service from Wansbeck General Hospital. Will complete the questionnaire based on the plan if it is of any interest.

Survey No 48 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Just started a hospital at home scheme this month still waiting to find out full scope of service but brought in to facilitate early discharge. Also have paediatric patients at home. Send questionnaire and he will try to find out if there are any of these patients being treated at home.

Survey No 50 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Minimal input. Some patients go home on ivs and the pharmacy supply the drugs but just on a TTA or outpatient prescription, not aseptically prepared. The patients administer the drugs themselves and are taught to do this by the nursing staff. Would like to aseptically dispense these items but there are no resources available to set up such a facility. Would like to go down this route but funding and staff levels do not permit. Quality issue. Medical audit is carried out from individual directorates and pharmacy are getting more involved in this. Would be interested to see questionnaire, will answer anything relevant.

Survey No 53 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic service. Minimal input about one patient per year who they provide with one-two weeks of home TPN and supply heparin syringes before the care is taken over by Caremark (Fresenius). Will answer.

Survey No 57 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic service with licence. No input usually but occasionally fill CADD cassettes for chemotherapy patients. Will answer questionnaire.

Survey No 58 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic service. Bit of home chemotherapy, no home TPN, no iv antibiotics, no desferrioxamine, have made up ganciclovir for the odd patient. Will complete questionnaire as long as not too long and you don't want it back in a rush! Aseptic Dispensing Services Manager

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Survey No 61 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Maria Hogg, yes we have a pharmacist designated to home antibiotics for mostly cystic fibrosis and AIDS patients (In on Thursday, Sally Allen ext 22689). TPN is dealt with through the Royal Victoria Infirmary. Sally Allen 6/11/97. We provide antibiotics and antivirals for hospitals all over the region. Have a licenced aseptic unit. Large hospital in Cleveland, Cumbria supplies some hospitals and there is a big centre in Leeds, either Seacroft or St James' who have lost a contract to a commercial company in the last six months. Chemotherapy, mostly 5FU in internates is also made up, Stephanie Klyne is the pharmacist responsible for that in the aseptic unit. Make it up for Freeman Group of Hospitals. Can't understand why they didn't mention it. Send two questionnaires and she will fill out one and ask Stephanie Klyne to fill out one.

Survey No 64 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic suite. pharmacist off sick. Senior tech - 1 patient on home TPN for the whole 9 years that I've been here. Originally came from Manchester and has recently had a change in fromulation advised by Manchester. Is sure that David Young the pharmacist will fill out a questionaire. Sent with note.

Survey No 66 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic dispensing but no licence. Possibly have one TPN patient who is looked after by someone else, I'll check. Cystic fibrosis patients have home IV antibiotics but the pharmacy do not reconstitute them they just disoense them and the patients make them up themselves at home. Will try to answer questionnaire.

Survey No 70 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Supply desferrioxamine but the district nurses go in to the patients homes and make up syringe and give it. No TPN, no antibiotics but do have a clinical trial going on at the moment sponsored by Lilly giving gemcitabine as an infusion at home. The pharmacy make it up and the patients are trained and looked after by a nurse specialist from a private company who goes in to the patients home to administer the drugs. have treated children on an outpatient basis with ceftriaxone in the past but they tend to come into the hosital on a daily basis. Will answer questionnaire.

Survey No 72 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments John Harwood, Pharmacist Aseptic Services 4812/4833/4807
Yes have patients on HTHH but do not supply the drugs. mainly TPN patients, speak to our nutrition team pharmacist Paul O'Brien. A commercial company have been contracted to supply the care, they have had a trial of 3 different companies and he thinks that one has just won the contract, ask Paul (01482 674411). Paul O'Brien - yes have one home TPN patient at the moment but have had six patients go through the process. care provided by a commercial homecare company. Will fill in a questionnaire.

Survey No 73 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Do lots of HTHH. Met him in Antwerp last year. Send the questionnaire. Went to Homecare '96, what was Homecare '97 like, any good? Any other conferences?

Survey No 74 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. No current patients. One cf patient on TPN supplied by Caremark and cf antibiotics supplied by Caremark. We supply initailly if the patient has been in hospital. Have a paediatric pharmacist who liases with the homecare nurse and consultant. Had one potential home TPN patient but they died. Will fill in the questionaire.

Survey No 76 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments No home TPN, few home antibiotics for cystic fibrosis patients give one-two weeks of abs at home. Also do weekly infusions of 5FU. Licenced unit. will answer questionnaire.

Survey No 78 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Do have aseptic unit but not of the best standard. Thinks region will soon close it down. No home TPN. Make up syringes of antibiotics for a couple of cystics. Will answer questionnaire.

Survey No 79 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic suite. es have several patients, no TPN but gCSF goes out into the community. Do not standardly do antibiotics but have a manufacturing unit which sends out intermates, don't know much about that but will try and find out.

Survey No 80 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Also Phil Deedee, TPN and David Ogwen, HIV. Do paediatric and adult tpn and antivirals. Cockrigde in Leeds deal with the chemo patients. Will try and fill in the questionnaire and pass it around to other pharmacists to fill in the appropriate parts.

Survey No 82 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments Pharmacist just left job. Do home chemotherapy, make up syringes in unlicenced aseptic unit. (Do civas, tpn and chemo for inpatients). Will try and fill in questionnaire.

Survey No 83 *Region* N&Y *Pharmacy* ☑ *Send questionnaire* ☑

Comments 2 patients on home TPN hospital pays commercial companies to provide this one is through Kabi and the other through another company. One was initiated at Leeds and one at Hope Hospital, Salford. Over the past two years have had 4-5 cf adults receiving antibiotics at home and about the same number of children, Have filled CADD and Walkman bags and Graseby pumps VADD and Cytaribine on an intermittent basis using Graseby pumps. Have approval to buy two more pumps to use in palliative care. have treated 4-5 palliative care patients with medtronic pump - implantable reservoir, DN fills and patient controlled. Diamorphine and bupivicaine +/- clonidine. Do you know anything about Abbot pumps as anaesthetist has seen rep for these and we want to talk to someone who might know their advantages/disadvantages for home use? ISOPP in Exeter.

Survey No 85 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Pharmacy at Basildon Hospital. Yes we supply home TPN, community paediatric nurses deal with home antibiotics for children. Speak to Peter Croot ext 3162.

Spoke to Robin Miller at Southend (129) he does compounding for this Trust too. Will anwer their questionnaire.

Survey No 88 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Not really. Have done desferrioxamine at home for an anaemic patient. Send questionnaire.

Survey No 90 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have a compounding unit but not licenced. Do make up ganciclovir ring ext 8395. Have got loads of patients on ganciclovir but contracted to Charing Cross. Do some home chemotherapy in Baxter or CADD pumps we provide 14 days in a 50ml syringe and the nurses inject it into the pump. Don't do much HPN. No antibiotics, have one patient on deferral via a Baxter pump at 5ml/hr which is filled every couple of days.

Survey No 92 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have a licenced aseptic unit and make up ganciclovir, foscarnet and amphotericin for HIV patients.

Survey No 96 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic yes but gone home! Do not have a pharmacist who has day to day input. Make up chemotherapy for a couple of patients 5FU, fludarabine etc. Looking to take on HTHH. Pharmacist at Essex County, Tracey Chapman, supply with chemo. Will answer the relevant parts of the questionnaire then pass on to Tracey Chapman.

Survey No 97 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Preparative Services Unit Manager. No iv abs or tpn but do make up chemotherapy in ambulatory bags in the pharmacy department, usually vincristine or doxorubicin. Will answer questionnaire..

Survey No 98 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Phoned DI to ask who to speak to -> Sue Patey, Pharmacist. Sue Patey 12/11 Do mostly home TPN through a commercial company. Tendering process for 3 year contract. 15 months left before retender. Do some but very few home abs and chemo because we are a tertiary centre and prefer the local hospitals to take this on. If the patient is under the host purchaser we are more likely to do it, otherwise run into problems when other places have other contracts.

Survey No 99 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments All hospitals in the Trust have pharmacy departments. Hammersmith (A) - occasionally do home tpn, no home abs, no chemo. Speak to Gerda Viedge, pharmacist. 0181 3834711. Gerda Veidge 13/11 When patient goes home on tpn dietician, doctor & pharmacy arrange for their care to be taken over by a home care company either Baxter or Healthcare at Home. Sometimes make up syringes of chemotherapy for patients to take home. Karen Hamling, more senior production pharmacist. (Boyfriend Loader)
Charing Cross (B) - 0181 8461869. Nicola Hooper, senior Pharmacist, Aseptic Services. Have one desferrioxamine patient. Provide HIV service for the Chelsea and Westminster (see 90) as they do not have a licenced unit (speak to Azeem Ahmed there). A little home chemo, patients start using Baxter infusers on the ward and then continue at home. Make up methotrexate syringes for National centre for trophoblastic disease, cycles every 2 weeks, either the patient comes in as an outpatient or the DN gives it at home.
Acton Hospital no aseptic.
Queen Charlotte's Neonatal & Maternity Hospital (C), have a very small unlicenced aseptic unit. Beryl ext 33915.

Survey No 100 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments No aseptic, speak to Alex Denby 01895 828595. Have a few patients on ganciclovir arranged through Baxter at Mount Vernon. Send questionnaire to transplant pharmacist Bhulesh Vadher. Sent with note.

Survey No 103 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit at Oldchurch Hospital,ext 3446.
1 home TPN looked after by Trust nutrition team. 1 deferral patient looked after by gp. Make tpn for Caremark - 12 patients at the moment.

Survey No 109 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Broomfield Hospital Pharmacy, Licenced aseptic unit. sometimes have home TPN, Don't know about chemo, Walkmed infusions? will find out. Send questionnaire.

Survey No 111 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Watford pharmacy no aseptic. Have a lady on ceredase or cerezyme buy service from Caremark, all we do is organise the prescriptions.
Mount Vernon -> speak to Dr David Melzac, 01923-844474->Do home chemotherapy infusions. We have a Baxter unit on site who make infusers of 5FU etc. The pharmacists have a lot of clinical input, there are three oncology pharmacists. Andrew Hood would be a good person to ask but on holiday. Send me the questionnaire and I'll pass it on to him.

Survey No 114 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Senior Pharmacist Prepartive Unit. Aseptic. One patient having desferral, we made it up for a while now we buy it from the Royal Free. No home TPN these patients would be under the care of the teaching hospitals.

Survey No 116 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have an aseptic unit and have applied for a licence. No home tpn or abs but occasionally make up chemotherapy in Baxter intermate infusers for patient to start in the hospital then take home.

Survey No 117 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have a licenced aseptic unit and make up home chemo (mostly 5FU) and ganciclovir. Jenny pharmacist 3069.

Survey No 118 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licenced aseptic unit. Have 65 home care patients. Provide tpn to patients all over the country even in Scotland. Hope in Manchester are the other people who supply a lot of home TPN. BANS - British Artificail Nutrition Survey think the register is now held at GOS (or maybe Birmingham Childrens or Hackney Childrens) we used to have it. Will answer questionnaire.

Survey No 120 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Did have patient on home TPN for 1 year, died last week. we supplied the TPN on a weekly basis. Home antibiotics mostly for paediartics Also some home chemo. District nurses or community outreach nurses care for the patients, take gentamicin levels etc. Aseptic suite is being rebuilt so get supplies from another licenced unit at another hospital. Will send back questionnaire if it's OK with the Pharmacy Manager.

Survey No 123 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licenced aseptic unit. Nicola Holt, Principal Pharmacist/ Acting Head of Dept also does paediatrics, send to her. Spoke to Helen Morgan.

Survey No 124 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Technical Services. TPN in manufacturing unit, Antibiotics in CIVAS. No cutrrent home TPN but are in the process of arranging for a child to go home. No antibiotics at the moment but do home desferral. Have 60 patients from other hospitals that they supply with desferral and 12 TPN patients from other hospitals. Will distinguish between patients that belong to our Trust and those that belong to others in the questionnaire.

Survey No 125 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Danny Murphy, TPN pharmacist. Whitechapel 20 desferral patients, TPN -> Caremark/Fresenius so don't make it. St Bartholomews have patients on ganciclovir in intermates and other antibiotics. Will answer questionnaire.

Survey No 126 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic service. Spoke to DI send to Caroline Websteer GI Pharmacist. Mostly make up 5FU for patients at home.

Survey No 129 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Principal Pharmacist Technical Services
One patient from this Trust on home TPN. Basildon and Thurrock Compounding unit used. Use Pharmacia regimens. £ TPNs at 85 now diong 6-7 which Kabi wholesale from there. Will answer questionnaires for 85 and 129 as provides the service to both Trusts.

Survey No 131 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Judith DI, speak to Judy Keene, Acting Chief Pharmacist/ Head of Production 0171 8866121 direct line (back from leave on 19/11/97). Have had patients on HPN and ganciclovir but have none at the moment. TPN patients have died. We buy in ganciclovir from Healthcare at Home. We used to make up the TPN. Distribution was taken over by Healthcare at Home. The paediatric pharmacist has a lot of clinical input. Will answer questionnaire.

Survey No 133 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Pharmacy, Basildon Hospital. Community paediatric nurses go to patient's home and administer antibiotics. Will answer and discuss questionnaire with Robin from Southend who also provides aseptic services to this Trust.

Survey No 135 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Could you post us a letter asking what you want to know? Send questionnaire to Tony Murphy, Principal Pharmacist with note. Aseptic unit no current home patients but have had 1-2 in past.

Survey No 139 *Region* NT *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic. Chrissie Cock 0181 5655883. Ring pm 13/11/97. Have the odd patient. Sometimes buy in the services of Caremark for TPN etc. Paediatrics we make up in the unit and the paediatric team look after them.

Survey No 142 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic but under refurbishment. Home TPN is made up by Caremark. Small involvement in their care. Surgical and Medical Units are split aseptic is based in the surgical unit so although they may have some input with surgical patients they have none with medical patients. Monitor biochemistry, discuss with consultant 2 desferral patients dealt with by Caremark, very little input with these. Will anwer questionnaire.

Survey No 143 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic, no licence but upgrade in process. Caroline Boardman deals with the cf patients. Buy in care for them.
caroline Boardman - EL(95)5 2 cf patients received IV antibiotics through Caremark. Pharmacy now order on behalf of the patients. Also had two patients on ganciclovir at the time. Looking to start making up their own eg ceftazidime for cf, costing to make a bid to the purchaser as an alternative to purchasing from Caremark. Some cf patients are trained to make up and give their own antibiotics with support from a paediatric outreach nurse. Have two patients on ceredase but they make it up themselves.

Survey No 145 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have a licenced unit but ganciclovir is made up in an unlicenced aseptic unit. Unusual to have patients being treated at home. No HPN, one patient on ganciclovir will find out if any others. Send questionnaire.

Survey No 146 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. In the middle of a licence application, when have it will competitively tender to provide the service. At present Caremark, Fresenius do it. Most important is cf antibiotics there are quite a few and a few TPN patients. There are two districts under one HA the other district is Blackburn.
Have also had a project running for 11 years for terminal care. Make up vast numbers of diamorphine syringes for patients to use at home (200-300/month) Have 48 hours expiry. Pharmacist educates groups ie they now do not ring until they have tried the oral route, they sort out laxatives, antidepressants etc first and then ring in advance of needing the prescription with starting doses of 100mg not 10mg. Cover whole area. Have a large advisory role. Work very closely with the gps in the area. District nurses love it, they also send out a spare label to stick in the patient's notes when the syringe is used to record what has been given. make up all sorts of things. Try to discourage three items in a syringe. Will answer questionnaire.

Survey No 149 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit, Pam Harris - but going on maternity leave so send questionnaire to Debbie Jones, Senior Pharmacist. Buy in HTHH from commercial company, Caremark, Fresenius. Have cf patients being treated at home with antibiotics.

Survey No 154 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have a licenced Baxter unit here at Christie's make up 5FU etc for Infuser B and Meric pumps. Patients come to the hospital every fortnight to collect.

Survey No 155 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic at Wirral Hospital NHS Trust 199. Arrowe Park 0151-334115 ext 2832. Have the odd patient who has chemotherapy at home with a pump. Have cf patients with antibiotics and TPN.

Survey No 158 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have 2 home TPN patients. Make up TPN in a licenced unit. Send questionnaire.

Survey No 161 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Yes have 2 patients on HPN made up in a licenced unit. Send questionnaire.

Survey No 165 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments We have a few patients. Some through EL(95)5 but there is arguement over whether cf patients are covered by this. An exception was made after April 1995 about numbers and the HA stepped back and tried not to pay. 1 child is having iv antibiotics under EL(95)5 and Caremark provide the antibiotic in a bag. There are another 2 patients who get the antibiotics from their gp and make them up themselves and 3-4 who get antibiotics from the hospital but they have to make them up themselves. We are a district general and the nearest tertiary centre for cf is in Manchester. A consultant comes up from Manchester every 2 weeks for a clinic. The pharmcists do have some input but not really on choice of drug or dose more the practical management of problems that arise.

Survey No 168 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit but not licenced. Have a lot of patients on home TPN - Caremark. Community liason pharmacist deals with these. No home chemotherapy but do have cf patients receiving iv antibiotics at home. Home patients _ Booth Hall speak to Soni Bhatt.

10 HPN paediatric, Caremark just provide the bags. Send a questionnaire.

Survey No 171 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Make up antibiotics for cf patients to use at home in the unit and give them a 7 day expiry as we have no licence. Patients who need home chemotherapy go to Christies.

Survey No 172 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. One patient treated with ganciclovir at home using an eclipse device. Make up in an unlicenced unit. (Spoke to Jeanette but she's going on maternity leave so send to Lynn).

Survey No 174 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit - unlicenced. Patients who have tpn at home are managed by Hope Hospital in Manchester. Have thallasaemics who are funded from region.

Survey No 176 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments No aseptic unit. Not many patients having home care but those who do arrange with Caremark to look after them. Have had patient receiving intensive antibiotics at home and also a tpn patient that Caremark dealt with. Quite a lot of input from pharmacy staff. Will answer questionnaire.

Survey No 177 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Acting Sterile Production Manager. Licenced aseptic unit. Have 2 home TPN patients. TPN is made up in the unit. Don't have anything else.

Survey No 178 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Yes do hane HTHH patients. 1 home TPn which we make ourselves and 2 which are looked after by central Homecare. Occasionally have home iv antihiotics which are dealt with by commercial home care company.

Survey No 180 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licenced aseptic unit. Make up home TPN and also ceredase infusions.

Survey No 182 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Do home gemcitabine for non-small cell lung cancer and ganciclovir post-transplant (give it a 5 day expiry). Have 220 adult cf patients, more than we can cope with. Will now only acccept cf patients as adult at 18 rather than 16 which was the age in the past, shame becausedon't build up such a close relationship with the patients when you don't get them until 18. Occasionally make up antibiotics for someone who is critically ill but able to stay at home. Could not cope with the work load to make them up for all these patients for their regular treatments. Have a large region to cover so transport would also be a difficult problem. Spend £90,000/month on the drugs bill for cf patients already. I think we provide a poor aseptic service but I'll fill in the questionnaire.

Survey No 184 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Don't have any patients currently being treated at home. Did have one tpn patient for a short time. Have also done ganciclovir and vincristine/adriamycin or vincristine/mitozantrone as a 4 day infusion as part of the VAD regime.

Survey No 186 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Occasionally have paediatric patients who have home antibiotics. Hospital at home nurses take drugs that are made up in the unit to the patients home. They are given a 3 day expiry. It's mostly cf patients and occasionally for meningitis. Caremark do the home TPN I think and patients who need chemotherapy come in to the day case unit to have it.

Survey No 187 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Do home TPN for one patient but it is generally catered for by Hope Hospital. Home ivs for paediatrics, the home care sisters go in on a daily basis to the patient's home to administer.

Survey No 191 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Hope Hospital in Salford deal with the home TPN and have TPN compounding unit. Christies have a Baxter chemo unit and deal with that. We have one lady who we make up a desferrioxamine cassette for.

Survey No 192 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Only have one HIV patient who collects his foscarnet from us once/week.

Survey No 194 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced asepic unit. Had a TPN patient who was referred to Caremark and we had no input. We have an asthmatic patient on aminophylline. CF patients reconstitute and administer the antibiotics at home themselves. The respiratory nurse looks after them. Pharmacists really only have an input when they are admitted.

Survey No 195 *Region* NW *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Don't have anyone right now. Have had someone on vancomycin at home over the last two weeks. John -tech

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Survey No 207 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have a licenced aseptic unit. Make up terbutaline infusions for 7 patients. Had one tpn patient but Caremark do it, don't even know if it is still current.

Survey No 208 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic. Have had patients at home treated on an ad hoc basis. Fill the bags of Walkmed pumps for chemo patients and McMillan nurse sorts out the pump. Don't make up any antibiotic infusions, community paediatric nurse trains patients to draw it up themselves. May even go through GP. Desferrioxamine, diamond black fan - patient chooses to come in for treatment, father consultant, mother gp.

Survey No 212 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Sterile manufacturing unit. Sue Harding/Adele Jones job-share. Make up terbutaline in intermate devices. Just started. Hope to take on TPN but Caremark do it now. Have been asked to do deferral but at the moment the patients come in to have it administered.

Survey No 214 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. No input. 1 anorexic man had TPN at home. Had 50 days TPN before fit enough for surgery. Aseptic unit made it up and he came in on a couple of days a week for a review of his condition and to collect. One chemo patient has 4 days of vincristine/doxorubicin made up. Don't know of anything else. Paediatrics and chest patients with long term infections have antibiotics at home but manipulate them themselves.

Survey No 219 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licenced aseptic unit. Provide HTHH.

Survey No 220 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Occasionally have an oncology patient who wants to go home for a while but is on TPN, the bed is usually kept for them and we make up 3 bags for example to allow them to go home but they can come back in any time that they feel ill. Have patients on Baxter infusers or Graseby pumps, VADD regime. Have one patient on desferrioxamine but don't do any home iv antibiotics.

Survey No 222 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licenced Manufacturing Unit separate from the pharmacy at Queen Alexandra Hospital. Bob Lucas, Pharmacist yes, the number varies. Now supply 1 adult on home TPN , make up the bags and the flush syringes. Also provide TPN for other hospitals, sometimes people can not cope with the demand or do not have licenced facility so can not give long enough expiry.Jacky Collett the nutrition nurse co-ordinates the home patients and takes responsibility for implementing and setting up home care as we are purely a manufacturing unit with no association to the pharmacy. Major companies still get involved like Baxter, Kabi, Fresenius, Unicare, Health Care at Home. Have some cf patients receiving iv antibiotics. St Mary'd deal with chemo speak to Tracey Evans. Do have home chemotherapy. We make up but it is all dealt with by the oncology/haematology nurses at QA.

Survey No 223 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Had 1 TPN patient who died ages ago. Have home antibiotics eg ganciclovir but a commercial company deal with it. Heamatology patients come to the ward to receive drugs.

Survey No 224 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Paul Evans Haematolgy Pharmacist ext 2598. Have 3-4 patients and negotiate on an individual basis with Caremark for each patient. I for example a patient needs to finish a 10 day course of antibiotics like ceftazidime and they have the last 4 days at home they will make it up in the pharmacy but any long term patients such as cf patients or the 1-2 Gaucher's Disease patients are dealt with by Caremark. I think we have one TPN patient being looked after by Plymouth and the HA pay directly for that, PHT sort it out.

Survey No 225 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments see pilot

Survey No 227 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Lesley Woodhouse need to speak to her qun sent 4/12/97(A) Aseptic unit. Do have patients on home IV rehydration electrolyte fluids, home antibiotics, TPN and make up bags for Walkmed pumps for home epidurals.
Jacky Davies (B). Have a satellite pharmacy in the Radiotherapy/Oncology Dept that make up chemo. Make up chemo for Health Care at Home. Do quite a bit but most people they supply live in the Bristol area.

Survey No 228 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. ext 4450 Have one home TPN patient in Jersey who has been feeding for 15-16 years. Fly it over from Southampton.

Survey No 229 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments No aseptic. Not involved in the supply. TPN is supplied by a commercial company ordered through the District Nurse budget. Mr Brian Cope is the nurse responsible for the DNs 330236. Pharmacy have no involvement with TPN patients as commercial company contact patient on discharge and they are usually discharged from the acute Trust. We are the point of contact if there are any pharmaceutical problems with patients receiving chemotherapy at home but nurses just go in and drw up sraihgt forward injections otherwise the patient goes to the hospital. Community Services Pharmacist based in a Pharmacy in a Health centre with another pharmacist running the shop. Have 4 community hospitals.

Survey No 230 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Have some HTHH patients will complete questionnaire.

Survey No 232 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. The Health Commission contract directly with Caremark. 4 TPN patients 3 attend the hospital nutrition clinic one is dealt with by Hope Hospital and the only input is that the Health Commission pay the bill.

Survey No 233 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licneced aseptic unit. Home TPN patient supplied by BRI. Would supply ganciclovir at home but have no need for it at the moment.

Survey No 234 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. No HPN. Have some home chemo in intermate devices which the DN goes out to change. Have taken over from Oxford in supplying these patients. Have patients on home iv antibiotics but think they make them up themselves the dispensary deal with it. Spoke to Ewan covering for Lindsay.

Survey No 235 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licenced aseptic unit. Have a couple of patients on algluterase. 1 is made up in the aseptic unit, the other the patient makes up for themselves.

Survey No 237 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments

Survey No 238 *Region* S&W *Pharmacy* ☑ *Send questionnaire* ☑

Comments Don't have any patients at the moment. Have had iv antibiotics, ganciclovir and one TPN patient. A company, Baxter or someone supplied it. We are not a licenced unit and at the moment have no unit as work is being done. We buy what we need from Portsmouth. Spoke to Senior Tech Alison Thomas.

Survey No 244 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Have patients on home chemotherapy via Graseby pumps who come in once a week. Buy the syringes in from Caremark.

Survey No 250 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments No home TPN patients. Paediatric ward sends patients home on iv antibiotics but we don't make them up. Have a paediatric home care team. Nurses go in to administer the antibiotics. Have one patient on desferral and we get Central to make that up.

Survey No 256 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Primarily cf patients on antibiotics but we do not make them up. Send us a questionnaire and we'll see if we think that we have any information useful to you.

Survey No 257 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. No HPN. Have patients on CADD pumps receiving 5FU for 7 days. Also have a desferrioxamine patient. Send questionnaire and I'll pass it on to a colleague who knows more about it than I do.

Survey No 258 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Pharmacists and technicians counsell patients with pumps for chemo mostly 5FU. It is all dealt with through pharmacy. Oncology (A) Mrs Roselyn Shakespeare-Miller, Senior Tech, Howard Rogers Pharmacy, Samaritan Ward, 8th Floor, New Guy's House, Guy's Hospital, SE1 9RT. Send 2 questionnaires and I will pass the other to the most appropriate person in the Manufacturing Unit (B), they make up ganciclovir etc. St Thomas' - no HTHH from here Paul Tunstall at Guy's is trying to set up a home ganciclovir program.

Survey No 259 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Have patients who come in once/week for pump change for their 5FU but that is all.

Survey No 261 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Have no HPN. Once years ago had a nurse who was terminally ill and did it for a short time for her. We have a pilot project giong on in our cancer centre where nurses are sent out to give chemo to patients at home. There is a Homecare team for paediatric oncology and they sometimes have 4 days of cytarabine. Have patients with 5FU pumps who come in to the cancer centre once/week to have them changed. Pharmacists do have a clinical input before the drug leaves the dept, check bloods etc.

Survey No 262 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Small aseptic. Had one patient on doxorubicin/vincristine 4 day infusions.

Survey No 263 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Presently unlicenced aseptic unit but hope to get one soon. Have 3 adults on HPN and one child. We are just about to start a second child. We also have cf patients with antibiotics etc. We do not make them ourselves but use a commercial company and the Royal Free make it up for the company.

Survey No 267 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic. No home chemo. Home TPN supplied by Caremark. Home antibiotics supplied by Lily. Don't make up any ourselves. Sometimes dispense iv antibiotics on a TTA.

Survey No 269 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Had a child on TPN. Buy in ready prepared bags and make additions.

Survey No 271 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aspetic unit. Satellite oncology pharmacy, some patients have 24 hour pumps. We have one shared care patient with St Georges. We used to sort out the TPN but St Georges do it now because it got too complex for the doctors and pharmacists here. Have the odd cf patient who does their own antibiotics at home. Do not provide much of a CIVAS service. Will fill in quesionnaire then pass to oncology pharmacist to complete.

Survey No 275 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Deal mostly with Mantal Health and Learning disabilities. Have a hospital at home scheme and pharmacist visits to assess pharmaceutical needs. Send questionnaire and I'll show it to Beth and ask if we have any input.

Survey No 282 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Have a number of patients on 5FU at home. ECF Regime. Occasionally have a HPN patient, only had 2-3 ever.

Survey No 283 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. No-one at the moment, have had a number of people in the past TPN, cf antibiotics, HIV ganciclovir, desferral. Have also supplied special insulin dilutions, epidurals for terminal patients and terbutaline infusions.

Survey No 286 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Fill pumps for 7 day continuous infusions of chemotherapy but just supply the drugs. Chemotherapy nurses have all the other input, counselling patients etc. Have had a couple of TPN patients I think but pharmacy did not get involved. I will try and find out who did it. Send a questionnaire.

Survey No 287 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Make up 5FU pumps in a licenced manufacturing unit. Pharmacy have a lot of input.

Survey No 292 *Region* South Th *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit being refurbished. Only have continuous chemotherapy. Will complete questionnaire.

Survey No 297 *Region* ST *Pharmacy* ☑ *Send questionnaire* ☑

Comments Do the odd chemotherapy pump for VADD regime. Have problems with or air handling unit so can't do TPN etc at the moment.

Survey No 300 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. It is a rare occurrence. Have one patient currnetly on intermittent courses of cytarabine subcutaneously and he has been taught to give himself twice daily injections for a week, repeated roughly every month. Have a patient who has ganciclovir at home, she comes to the hospital once/week and picks up a weeks supply. I think the DN goes in and infuses it. Most of the TPN etc is based at Sheffield. Have had HPN in distant past for scleroderma patient.

Survey No 302 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Mansfield Community Hospital. Yes we do home iv antibiotics. We don't have any manufacturing facility. We started an intensive home support scheme a month ago. There are currently 10 patients being looked after in their homes either referred from hopistal or by their gp. The pharmacist visits them. Nurse make up the antibiotics in the patients home. Pharmacist gives advice. Send questionnaire.

Survey No 303 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Make up antibiotics for cf patients etc in licenced part of pharmacy. Use a commercial homecare company to supply TPN.

Survey No 304 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Most HTHH is from tertiary referral centres in Manchester or Leeds. Did make up algluterase for 3-4 months to allow time for caremark to sort out taking over. Summer symposium BAPEN July next year, will you present your work?

Survey No 307 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Yes have intensive home nursing service. Don't get involved with the supply. Do iv antibiotics at home and iv fluids for rehydration.

Survey No 308 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Most of the HTHH patients would be looked after by the DRI. We do supply desferral for paediatrics. We have a nutrition sister but the DRI would take over if needed HPN.

Survey No 309 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Yes we do it. Yes I'll fill in the questionnaire.

Survey No 312 *Region* Trent *Pharmacy* ☐ *Send questionnaire* ☑

Comments No pharmacy but have a pharmacist. Yes we operate a hopsital at home service. Antibiotics etc are probably made up in the patient's home or bought ready prepared. Nova Pharmaceuticals prepare in their manufacturing unit, provide ready prepared chemotherapy syringes. Fosse Trust provides nursing input, gp generally looks after the patient. Leicestershire DG Hospitals provide guidance to the gps.

Survey No 315 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments No TPN or antibiotics but we do CADD pumps for chemotherapy in a licenced aseptic unit.

Survey No 317 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Occasionally make up iv antibiotics for patients to use at home. Use Caremark for other things such as desferal. Have 1-2 TPNs that either Caremark or another company deal with. Chemotherapy we provide from the lab. The ECF regime that we used to do seems to have died a death recently.

Survey No 318 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Have one patient on HPN which we get from Clinitec, Baxter's division. We do the additives and package it off to the patient. Chemotherapy use Baxter infusers and CADD pumps for 5FU.

Survey No 321 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit working under Section 10 exemption. Have cf patients on antibiotics but currently this is mostly provided by Caremark. Have one domicillary TPN patient under the care of Sheffield, feeds come from Caremark and are organised by the Northern General. Patients on home treatment for CMV we make up their ganciclovir in our cytotoxic suite. 3-4 patients are having adjunct continuous chemotherapy, 5FU. Make up 7 days supply in house. Also do 2-3 days of vincristine and doxorubicin. Have looked at doing the cf antibiotics ourselves but funding issues are a problem.

Survey No 322 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Have TPN patients at home but we do not make it up ourselves a commercial company does it.

Survey No 323 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licenced aseptic unit but make up home iv antibiotics for cf patients as a special in unlicenced unit. Sometimes we make them up and other times we use a commercial company.

Survey No 327 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Just do home TPN which we make up ourselves in a licenced unit.

Survey No 330 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. No HPN, one patient on 5FU infusion via a graseby pump. Have some cf patients whose parents are trained to make up and administer antibiotics. No iv additive service in operation. Ganciclovir and ceredase patients come to the ward for administration. Couple of patients on HPN prescribed and provided by other hospitals. May be 3-4, HA pays.

Survey No 332 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Yes do it for odd patients. We make it up ourselves at the moment but are about to close for three months for thre aseptic facilities to be upgraded.

Survey No 335 *Region* Trent *Pharmacy* ☑ *Send questionnaire* ☑

Comments Chemotherapy aseptic unit. No HPN. 1 lady on 5FU infusion.

Survey No 337 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Yes we do have patients. Send the questionnaire I'm in a meeting at the moment.

Survey No 338 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Have the odd home TPn patient dealt with by Caremark and use ready made Baxter's antibiotics for cf patients. Mike, Pharmacist, Yvonne cytotoxics.

Survey No 341 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Don't have anyone at present. Have the occasional patient on chemotherapy via Baxter infusers and we provide that.

Survey No 342 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Have the odd one. Desferrioxamine for a sickle cell patient and probably some home chemotherapy. Send the questionnaire to Brian Hebrown, Principal Pharmacist.

Survey No 344 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Make up 7 day 5FU pumps in the unit. Have aslo done HPN in the past. Will fill in chemo bit and then pass on to Sharon Ford to answer about the TPN.

Survey No 349 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit = isolators. None at the moment. Had 2 patients on HPN Caremark supplied everything.

Survey No 352 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Make up chemo but everyone comes in to the hospital to have it administered. Sometimes people have doxorubicin/vincristine in Walkmed pumps. They come in to the hospital to have it started and stopped. They are given written information about what to do in case of problems and a contact number.

Survey No 355 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Do iv antibiotics for cf adults and children. All HPN is dealt with in Manchester.

Survey No 359 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Have 2 patients on HPN, one patient who has brittle asthma we make up colomycin for nebulisation amd terbutaline for infusion. We also make up methotrexate syringes for sub-cutaneous use in a child weekly.

Survey No 362 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Andrea Foster. We do make up bags for a HPN patient. We do not supply antibiotics etc.

Survey No 363 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. No HPN. Few antibiotics for children on the hospital at home scheme. Also have a desferal patient.

Survey No 365 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlicenced aseptic unit. Did have a patient on HPN a while ago and would offer the service. Currently provide no antibiotics but there is interest in this and we are looking into it. Don't really advocate home chemo but do syringe drivers and elastomeric devices on an ad hoc basis.

Survey No 367 *Region* WM *Pharmacy* ☐ *Send questionnaire* ☑

Comments No pharmacy but have a pharmacist.

Survey No 368 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Licenced aseptic unit. Rarely provide ganciclovir or desferal for use at home. About once/year.

Survey No 371 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Caroline Hamilton. We have 2 hospitals in Selly Oak and it is all done at the Queen Elizabeth site. Speak to Jo Humphries-> 3 patients on HPN. Looked after by the clinical nurse specialist Lynn Colodjiavaney. Buy from Caremark, Fresenius. IV antibiotics for cf are dealt with by Harlands Hospital which is a different Trust. We also do chemo for patients at home speak to Jim Baker -> Unlicenced aseptic unit, not yet submitted for inspection. Make up chemo for patients to use at home in our unit.

Survey No 373 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Aseptic unit. Had one patient on home chemotherapy to finish a course. Do have a home chemo nurse. Do not use oumps as the delivery system. have very minimal input. Patients generally attend the outpatient clinic.

Survey No 374 *Region* WM *Pharmacy* ☑ *Send questionnaire* ☑

Comments Unlcenced aseptic unit but opening new premises at the end of March. Do have patients who have desferral in home pumps but might change this because don't have the stability data. Also provide continuous 5FU for oncology. provide syringes of 5FU for Graseby drivers.

APPENDIX

23

Expenditure On Home IV Antibiotics For Cystic Fibrosis Patients, Trust Questionnaire

Survey no	No of patients	Expenditure?	Explanation
3	5	£15,000.00	
12	1	£1,869.90	
17	2	£10,000.00	
72	25	£40,000.00	
74	4	£1,000.00	for pharmaceuticals only (?other costs)
79	70	£170,000.00	
83	8	£150,000.00	1 pt £80,000 total estimated cost £50,000 pa on drugs alone. Note: 1 patient on continuous antibiotics awaiting heart/lung transplant. total cost of drugs alone approx £80,000 pa 3 patients on regimes containing meropenem therefore cost of drugs alo
116	2	£10,000.00	less than? drugs only
123	130	£400,000.00	
146	3	£15,000.00	
165	6	£10,000.00	of which hospital £6000-£8000. Hospital pharmacy normally provides vials and diluents but on occasion we have supplied ready to use prefilled syringes. If Gp supply then they only provide vials and diluents.
171	8	£15,700.00	drugs only, current year projected.
219	2	£10,000.00	
227	1	£25,000.00	
230	2	£3,500.00	£3-4000 on iv antibitoics alone
244	2	£3,000.00	Drugs only about £500 per 2 week course, an average of 6 indcn/year = about £3000
250	1	£1,000.00	
317	2	£10,000.00	
321	12	£100,000.00	
323	47	£100,000.00	(Pharmacy 10% only)
332	3	£10,000.00	
355	32	£60,000.00	drugs/on call

Expenditure On Chemotherapy, Trust Questionnaire

Survey no	No of patients	Expenditure?	Explanation
1	20	£100,000.00	
3	2	£15,000.00	
37	3	£10,000.00	
74	4	£5,000.00	for pharmaceuticals only (?other costs)
83	8	£60,000.00	
116	4	£10,000.00	less than? drugs etc
117	6	£63,000.00	
174	3	£8,000.00	
208	5		sorry do not know equipment costs. Drug costs less than £10,000 but this could change
223		£25,000.00	only 5FU continuous infusions
228	5	£10,000.00	
234	2	£10,000.00	approx
258	27	£30,000.00	approx
261	12	£300,000.00	approx £30 per bag
271	20	£70,000.00	drugs and equipment
292	10	£20,000.00	drugs
323		£20,000.00	home
373	1	£160.00	Supply chemotherapy only. Course now complete.
999	14	£50,000.00	

Expenditure On Anti-virals For HIV, Trust Questionnaire

Survey no	No of patients?	Expenditure?	explanation
17	1	£20,000.00	
28	2	£60,000.00	
92	12	£30,000.00	
117	4	£126,000.00	
131	2	£40,000.00	
223		£10,000.00	100doses
250	0	£1,000.00	
300	1	£1,000.00	less than
317	2	£30,000.00	
323		£20,000.00	
999	2	£20,000.00	

Expenditure On Home Parenteral Nutrition (HPN) For Adults, Trust Questionnaire

Survey no	No of patients	expenditure	explanation
1	8	£250,000.00	
3	1	£10,000.00	
53	2	£20,000.00	cost varies - pharmacy cost for TPN only £20,000pa
72	5	£80,000.00	
103	1	£32,500.00	approx £30,000-£35,000
177	2	£100,000.00	
208	2		Drug costs about £400
219	2	£60,000.00	
227	1	£60,000.00	Part service of TPN
228	1	£10,000.00	excludes transport costs and equipment used by patient
230	1	£35,000.00	
282	1		£100 per day of TPN
303	4	£130,000.00	
322	4	£120,000.00	Approx £120K but this is paid for by the HA concerned.
327	3	£80,000.00	
359	2	£40,000.00	
2222	1	£18,000.00	

Expenditure On HPN For Children, Trust Questionnaire

Survey no	No of patients	expenditure	explanation
1	3	£90,000.00	
98	12	£700,000.00	approx
219	1	£30,000.00	
230	1	£35,000.00	
287	2	£80,000.00	approx 40,000 per patient
327	1	£25,000.00	
332	1	£15,000.00	£10-20K
337	5	£220,000.00	
362	2	£100,000.00	

Expenditure On Desferrioxamine For Patients At Home, Trust Questionnaire

Survey no	No of patients	Expenditure	explanation
3	2	£20,000.00	
12	1	£3,650.00	
79	10	£32,000.00	Desferral TTOs and desferral syringes in outpatients approx = £32,000 drug cost
116	1	£10,000.00	less than?
117	2	£20,000.00	
219	4	£10,000.00	
223	2	£10,000.00	
230	1	£500.00	drug alone
250	1	£2,000.00	
317	15	£10,000.00	for one patient on homecare pack, considerably less for the rest.
323	4	£20,000.00	
332	3	£10,000.00	
337	19	£140,000.00	
352	1	£2,196.00	so far!
999	1	£10,000.00	

Expenditure On Other Home Infusions, Trust Questionnaire

Survey no	specify	No of patients	expenditure	explanation
12	aglucerase	1	£22,248.00	
17	immunoglobulin	1	£50,000.00	
28	home iv antibiotics	60	£20,000.00	drugs, ancillaries not costed.
72	Gaucher's Disease/Ceredase	1	£30,000.00	
72	immunoglobulin	1	£20,000.00	
79	G-CSF	12	£52,000.00	G-CSF at home approx £52,000 drug cost not inc technical support and preparation of syringes
98	Cerdase	1	£120,000.00	approx
98	home CAPD	38	£500,000.00	approx
116	antibiotics - paeds eg meningitis once daily	0	£10,000.00	less than?
131	2 x Gaucher's Disease receiving Cerezyme 1x chronic liver pt receiving antibiotics	3	£500,000.00	drugs only
194	patient receiving aminophylline infusion	1	£30,000.00	
230	iv immunoglobulins, Iloprost	2		£8000 Sandoglob £60,000 Iloprost
283	home epidurals -occasionally			
332	2-3 oncology patients receive line locs for home use			£0-10K

359	Child methotrexate -arthritis	0		£4000 - not clear if this is for the adult on terbutaline or child on methotrexate or both

APPENDIX

24

Trust Survey: HTHH worked best, barriers and other comments

Survey no:	1
worked best	TPN more predictable and history of pharmacy involvement.
barriers	Unco-ordinated as an entity eg Nutrition team deal with TPN, Dialysis unit deal with dialysis etc
further comments	no
Survey no:	2
worked best	
barriers	
further comments	Dear Jill Many thanks for sending the questionnaires. Trust provides community services but the Trust has no pharmacy of it's own. Pharmaceutical supply and advice is provided by the Ipswich Hospital NHS Trust (acute hospital). The majority of patients who have home infusional therapy, have treatment initiated at the Ipswich hospital with link nurses etc based at the hospital monitoring patients in the community. Supply of advice and drugs are provided by the appropriate specialist pharmacists at the Ipswich Hospital NHS Trust. I have therefore passed on one questionnaire to the most appropriate pharmacist at the hospital. Allington Trust may provide district nursing care etc, to support the care provided by the acute unit. From discussions with various staff at Allington Trust I gather the role of staff in hi-tech health care at home is limited. training has begun on intravenous antibiotic administration by district nurses. The pharmacy input is therefore very limited and tends to be reactive rather than a proactive role. We hope this will develop gradually. The information I can provide is therefore limited. If I can provide further information please contact me on 01473 703606/5/4. I wish you all the best with your research. Best wishes
Survey no:	3
worked best	chemotherapy - regimens where patients had to sit in hsopital while the infusions were running - they prefer to be at home eg VAD, cyclo, VAD etc
barriers	No
further comments	
Survey no:	12
worked best	HIV - possibly because of their interest in self-medicating at home
barriers	financial support
further comments	

Survey no:	14
worked best	
barriers	
further comments	As a DGH we don't treat many of these patient groups. The two patients we have are entirely managed by a commercial home care company, the main pharmacy input being in the setting up of the contracts and liasing with patients, carers, medical and nursing staff to ensure that it runs smoothly.
Survey no:	17
worked best	
barriers	
further comments	
Survey no:	25
worked best	
barriers	
further comments	
Survey no:	27
worked best	iv antibiotic patients, organised system, good communication, follow-up, records, support for pt/carers and PHCT's
barriers	No real barriers - just sheer volume of patients at times for 2 woman home iv team to cope with.
further comments	This isn't a very easy questionnaire to complete as I work for the community Trust and cover all the acute hospitals so provide iv therapy broadly so it's difficult to answer questions that are specific. Please ring me if you need further information as I don't think this questionnaire does our service justice. I was very involved in the early stages of setting up the home iv service from this hospital - esp in formulating protocols. Since then I have had to take a step back due to lack of time - but Jill, the doctors and microbiologists and I liase closely.
Survey no:	28
worked best	
barriers	Complexity of drug regimens - tds and qds regimen impossible for a district nurse based service
further comments	
Survey no:	30
worked best	
barriers	
further comments	
Survey no:	31
worked best	
barriers	
further comments	

Survey no:	33
worked best	
barriers	
further comments	is a Community Trust with mostly rehab and psychistric beds. There is a palliative care ward but they do not do any hi-tech treatment at home.
Survey no:	37
worked best	1) "ECF" Regime chemotherapy (21 days continuous 5FU) 2) Barts Regime (48 hours continuous 5FU) Patients carrying on near normal life, not tied to large infusion volume IMED.
barriers	
further comments	
Survey no:	45
worked best	All patients prefer to be treated at home. So far there has been no major problems, service has been well received.
barriers	Large geographical area to cover. Relatively high transport costs.
further comments	
Survey no:	46
worked best	
barriers	
further comments	program not up and running yet, cannot answer the questions in the questionnaire.
Survey no:	53
worked best	
barriers	
further comments	Very rarely have patients on home therapy. Usually TPN patients for a few months. Recently home TPN patients have been taken over by commercial companies who have a less flexible approach to formulation changes such that the pharmacy depatment prepare bags when regimes have to be altered at very short notice.
Survey no:	57
worked best	
barriers	
further comments	
Survey no:	66
worked best	cystic fibrosis - no other group known
barriers	
further comments	Only area the pharmacy is routinely involved with is cystic fibrosis - pts make up the drugs themselves though we do have the facilities but not the funding. TPN patient known about though no other details. Best of luck with the study.

Survey no:	72
worked best	Nutrition. Well managed team approach.
barriers	Finanace limited by purchaser.
further comments	
Survey no:	74
worked best	Too little real experience to answer properly - it works for both (limited) groups of patients.
barriers	
further comments	As I said when we spoke on the phone our experience of home iv therapy is very limited - please analyse the answers with this in mind!
Survey no:	79
worked best	
barriers	
further comments	
Survey no:	83
worked best	Chemotherapy delivery has been successful. Caremark delivery of 5FU is reliable. Haematology patients receive chemotherapy prepared in-house, always commenced in hospital. Assessment of these patients is thorough.
barriers	covers a larfe rural population, therefore delivery of products prepared in-house is difficult - transport could be more efficient! Some child cystics are known to be poor compliers but are unwilling to be inpatients, therefore some improvement in selection and training may lead to better compliance.
further comments	I feel the pharmacy department is supllying hi-tech care to cystics 'on demand' without the back-up systems in place - similarly demand for 'one-off' epidural infusion at home is increasing, without sufficient liason (in my opinion) between district nurse/GP/hospital consultant re role and responsibility.
Survey no:	88
worked best	
barriers	
further comments	All our TPN patients are referred to St Mark's. Most oncology patients go to the Hammersmith, we do not use home chemo just day care. We have a collaborative care team who administer antibiotics etc at home. Our HIV patients go to St Mary's. We have a sickle cell centre in Brent.
Survey no:	90
worked best	HIV - ganciclovir for CMV retinitis. Patient compliance is good (they go blind otherwise!!)
barriers	None?!
further comments	

Survey no:	92
worked best	HIV patient - patients empowered and good compliance in this group.
barriers	None
further comments	
Survey no:	96
worked best	
barriers	being unable to find out what is currently happening
further comments	The situation is very complex -diffuse and vague accountability -very fragmented. In short - a mess!
Survey no:	98
worked best	Home TPN - enables patient to leave hospitaland achieve some measure of normal life. Home CAPD for same reason.
barriers	No problems with purchasers re TPN, CAPD but there may be problems in home environment. Ability of carer to cope, support available in community.
further comments	Please note: we are a tertiary referral centre with a number of purchasers. If possible we refer patinets back to secondary centre - who may then institute a home care package themselves. For those purchasers who do not wish for our TPN package we charge a nursing element only.
Survey no:	99
worked best	limited experience
barriers	
further comments	
Survey no:	100
worked best	Motivated transplant recipients (especially cystic fibrosis transplants).
barriers	Timing, patient competence, monitoring.
further comments	
Survey no:	103
worked best	n/a.
barriers	n/a
further comments	
Survey no:	109
worked best	
barriers	
further comments	
Survey no:	111
worked best	oncology patients - convenience/clinical indication/patient acceptability
barriers	
further comments	

Survey no:	116
worked best	Chemotherapy only used at present. Can be used at home without keeping patient in hospital and essentially blocking bed.
barriers	None
further comments	really sorry it's taken so long - good luck with your research, Marie.
Survey no:	117
worked best	All patients seem happy with treatment apart from problems with the flow rates - common to all patients.
barriers	cost, suitable suppliers
further comments	
Survey no:	118
worked best	Only do on TPN patients - works well because got dedicated team to teach patient, patients chosen for home care using strict protocols.
barriers	mainly financial
further comments	This is probably difficult to understand. We are a speciaist tertiary referral centre for GI disease therefore only see TPN patients that are suitable for home care. Wehave about 65 patients on home care TPN at present but they are not from local area. The hospital treats people from all over the country.
Survey no:	123
worked best	cystic fibrosis - our only group. We have large numbers of patients therefore familiarity with the system we have set up.
barriers	In the past the response time of the homecare company has been a problem as need for antibiotics is not planned.
further comments	Some answers incomplete as only recently taken over role of Acting Head.
Survey no:	124
worked best	The two areas we have particularly been involved with are TPN and Thallassaemia. TPN Has worked best because otherwise patients would have to be in hospital. Amongst thallaessaemics ferritin levels
barriers	Funding from the local HAs not available for all patients wanting home therapy and problems where a block contract does not cover sufficient patients. Where we are the tertiary provider some secondary providers only being prepared to work with Caremark. This HAs also arisen where we are supposed to be providing care for paediatrics but a paediatric hospital will only work with Caremark.
further comments	We have a small number of our own patients on home care but also prepare TPN, Desferal, HIV treatment and antibiotics for patients based at other hospitals, either as direct contracts or through Health Care at Home. The answers in brackets refer to patients based at other hospitals, the plain ones are our own patients.

Survey no:	131
worked best	Gaucher's - frequency of treatment once a fortnight.
barriers	Cost of HIV patients.
further comments	I'm sorry it's such a mess! I've collected information from three different specialties; paediatrics, chemotherapy/production, HIV all involved in hi-tech therapy. Where involvement is different I've put which specialty. If no comment it is all or the remainder. I hope it is of use.
Survey no:	133
worked best	
barriers	
further comments	Dear Jill We have decided that will include Trust in his questionnaire therefore I have not completed the form. and NHS Trust will be dealt with together.
Survey no:	142
worked best	Thallassaemics, because good communication/co-operation between haematologists and pharmacy.
barriers	Poor communication between surgeons and pharmacy for home TPN.
further comments	
Survey no:	143
worked best	Cystic fibrosis patients can receive treatment at home, less disruption to school
barriers	Main barrier to us preparing iv antibiotics has been production unit facilities - now undergoing ugrade so we should be able to prepare in house so long as funding given. Bid is going to purchaser for us to prepare iv antibiotics for cystics where want them prepared.
further comments	
Survey no:	145
worked best	
barriers	
further comments	None of our patients receive hi-tech care at home. They are under the care of specialised centres eg Christie Hospital who will then provide this service.

Survey no:	146
worked best	thallaesaemics,cystics and TPN does work well.
barriers	
further comments	EL(95)5 left grey areas such as diamorphine which IS hi-tech health care. Dear Jill the Terminal Care service offered by our hospital started about 10 years ago when a lady was started on a syringe driver on a ward then wanted to go home for her last few days. Our transport agreed to deliver to her home daily, our aseptic unit was already running 7 days a week and the staff all agreed that it was a very worthwhile product to provide. This proved very successful for the patient and her relatives, but also created a very positive perception with the district nurses. The IV additives service started in Burnley in 1972 and HAs developed over the years so that we now prepare almost 60000 units each year. This established the practice of pharmacists intervening and advising in the parenteral use of medicines almost from that time. I also developed an interest in terminal care so that when the next requests arrived, I became involved in the development of the therapy. This escalated over the next few years and in an attempt to validate the need for the service I started to enquire from the Gps the patient's clinical details. sometimes an equally effective and less intrusive approach was available ans acceptable, at the same time adjunct therapy could be discussed. As this developed, many GPs took on board the ideas and suggestions and became much more confident with very high doses (we have prepared and supplied 10000mg/day of diamorphine for one patient - yes 10grams!) so that we are now often only involved in the difficult cases when our opinions are sought about symptom control and adequate analgesia. Communications with most GPs are now excellent with the community nurses involved as well. The current level of service is for about 250 syringes each month for between 3 and 12 patients each day. The syringes are prepared daily and delivered to the patient's home or nursing home each day by hospital transport. We obtain FP10s for the legal nicety to supply, but cannot obtain any funding whatsover, costing the hospital at least £40000 each year. The failure to include any services outside their small range of experience by personnel not at the 'sharp end' has, and will in the future, severely restrict and curtail any advance in patient care in this area. We have tried every avenue to obtain external funding, all to no avail. Thankfully, the Trust Managers value this service to patients in their care and continue to provide the finance necessary, but this is coming increasingly more difficult. What for the future? I hope this gives a little insight into our service and provides what you are looking for. Please do not hesitate to contact me again. Yours sincerely

Survey no:	154
worked best	Continuous 5FU for colorectal patients and ECF regimen. reduces the number of times a patient is required to attend clinics.
barriers	depending on the area a patient lives, the district nurses may not be happy to change infusors. Therefore the patient has to return to the hospital weekly.
further comments	Due to the large number of patients being enrolled onto 5FU therapy it was inevitable that an infusor co-ordinator would be required. The service is not strictly speaking home care as the patients are required to collect their own infusors. We do not have a delivery service.
Survey no:	158
worked best	
barriers	
further comments	
Survey no:	165
worked best	
barriers	Trusts pharmacy aseptic facilities are not licenced and there is no practical way of supplying the full back up support required by EL(95)5 from the Trust. This means that the Trust itself is unable to tender and outside organisations have to be involved.
further comments	
Survey no:	171
worked best	n/a
barriers	
further comments	Commenced home iv treatment for cf children in June 1993.
Survey no:	172
worked best	HIV patients with CMV retinitis are our main experience with home care.
barriers	
further comments	
Survey no:	174
worked best	thalassaemics because pharmacy retain control
barriers	
further comments	
Survey no:	177
worked best	TPN only at this Trust at the moment
barriers	24 hour support, patient selection
further comments	
Survey no:	178
worked best	
barriers	
further comments	

Survey no:	180
worked best	TPN patients - good back up at the nutrition team.
barriers	
further comments	
Survey no:	187
worked best	Excellent for cystics via the home care paediatric sisters.
barriers	Yes. IV antibiotics for cellulitis/bacterial endocarditis due to lack of district nurse time and no real policy to state who provides ivs and consumables for HC patients (adults only).
further comments	
Survey no:	194
worked best	
barriers	cost factor
further comments	Have had dreadful trouble contacting the paediatric respiratory team - tel no 01925 6622633
Survey no:	195
worked best	
barriers	Pharmacy have never been asked to provide this
further comments	We are a small District General Hospital. Very few patients have hi-tech health care at home.
Survey no:	208
worked best	Chemotherapy, home TPN - these are our two main areas and we see them as successful on quality of life issues ie. patients spend less time in hospital
barriers	1. some patients prefer hospital treatment (health professionals within our Trust have chosen to have all their children's treatment at hospital even though they could have given it at home). 2. Non-awareness of possibilities of infusion therapies at home. 3. Difficulty of setting up on an ad hoc infrequent basis.
further comments	We are a small Trust - therefore the possibilities of EL(95)5 are less for us,. One contracting organisation (healthcare at Home) were quite active in promoting their service during 1995 (their area manager did some nursing in this hospital) and we did supply them with pharmaceuticals but found in reality there were very few opportunities. It is possible that a less aggressive approach could slowly build up this area of work. All activity at the moment is "as and when" although at one stage we were about to put protocols/care plans in place for home TPN.
Survey no:	212
worked best	Terbutaline pts - high motivation leading to normal lifestyle.
barriers	Money.
further comments	

Survey no:	214
worked best	Of the few patients treated at home, paediatrics probably gain most through children being at home rather than in hospital; parents are mosre actively involved in child's care. Parents able to involve themselves more in home/family life.
barriers	Finances- need to set up working party to identify suitable patient groups; design protocols; select patients; train pharmacy, nursing, medical staff and patients; select commercial company (if appropriate); etc etc
further comments	Pharmacy need to become involved in a Trust wide policy on home infusional therapy, rather than different areas doing their own thing and everyone pulling in different directions. In order to succeed nedd a large and continued cash injection to set the process in motion and keep it working properly.
Survey no:	219
worked best	TPN - patients are treated long-term and get into a routine. Also patients are well motivated and are generally quite well.
barriers	Lack of knowledge/awareness by prescribers. limited HA funding.
further comments	No!
Survey no:	222
worked best	Home TPn was very successful - we have had several patients over the years. Home chemo has taken off really well. New service for DVT is just starting.
barriers	Lack of nursing staff able to be released to set up practice.
further comments	The home care system as such has only recently been set up for mainly haematology and starting medical patients with DVT's. Old systems are in place for home TPN (but we haven't any patients at present but have had up to 4 patients at a time in the past). There are other pharmacists who have direct input into the group which was initially set up with a lot of support from the pharmacy/pharmacy management.
Survey no:	223
worked best	chemotherapy patients on infusional 5FU - only having to attend hospital briefly once a week.
barriers	Cost of devices has been a problem and workload but is now being resolved through negotiation with purchaser.
further comments	We have just had one adult TPN patient transferred from another area which has been efficiently dealt with via Kabi Pharmacia and the Health Authority
Survey no:	227
worked best	Cystic fibrosis - do not require hospital bed and can be with family. Electrolyte replacement- keeps patient at home.
barriers	CASH (OR LACK OF IT!)
further comments	

Survey no:	228
worked best	5FU works well. Home TPN patient fed approx 16 years at home.
barriers	
further comments	Not sure how applicable your questionnaire is to the service that we provide - however hope it is of help.
Survey no:	229
worked best	
barriers	
further comments	I am working in a Community NHS Trust covering the same geographical area as an Acute NHS Trust. All high tech provision is initiated in the acute Trust and the main input in the Comm Trust is via support from District Nurses/ health visitors
Survey no:	230
worked best	Don't know
barriers	Lack of facilities, staff, resources
further comments	Jill: These answers apply mostly to TPN as that's where I have involvement. We don't have much to do with the other home patients. (I did get and to look at the bits they knew more about than me).
Survey no:	232
worked best	
barriers	
further comments	
Survey no:	234
worked best	
barriers	
further comments	Most hi-tech health care done via health authority rather than Trust.
Survey no:	241
worked best	barrier to continue aseptic preparation in pharmacy is funding for the extra staff needed.
barriers	
further comments	
Survey no:	244
worked best	
barriers	
further comments	
Survey no:	250
worked best	?
barriers	?
further comments	

Survey no:	258
worked best	n/a
barriers	1. We've had language barriers where interpreters have been called upon to aid explanation to patient. 2. Patients whose mental/physical state plus home environment have proved unsuitable.
further comments	I have based my answers purely on the service/treatment we provide to oncology patients therefore have excluded/not able to answer unappropriate questions. I apologise sincerely for taking so long to return your questionnaire. I had problems persuading other areas to find the time to fill it in. I've therefore retreived it. Unfotunately it's not complete.
Survey no:	261
worked best	We only treat chemo patients with 5FU at home
barriers	Money (with regards nurses giving chemo at home)
further comments	The only patients I could think of were continuous 5FU pump patients who have bags filled weekly in Pharmacy but otherwise come in weekly to our cancer care centre for blood counts, line inspection etc. I can't think of any patients who administer drugs to themselves at home.
Survey no:	262
worked best	
barriers	
further comments	We have no involvement and as far as we are aware no patients receiving high-tech health care at home. Chemotherapy is mainly provided by , and thre may be some involvement from them.
Survey no:	271
worked best	
barriers	
further comments	Only 5FU infusion pumps/devices are prepared for home use. We are unlicenced therefore patients return every seven days for a bag change which is changed by a chemo nurse.
Survey no:	282
worked best	We only have experience of continuous infusional chemotherapy (5FU) and the occasional TPN patient, both seem to work well.
barriers	No immovable barriers. Transport, nursing care, line care.
further comments	
Survey no:	283
worked best	Home TPN -highly motivated patients. Cystic fibrosis antibiotics - motivated ward staff and paediatricians. Home epidurals - progressive hospice medical director with good links with hospiatl pain team consultant.
barriers	transport and delivery
further comments	These answers (as discussed) apply to Hospital, where I recently left from post of Senior Pharmacist Aseptic Services. They relate to my understanding at the time I left (end Feb 98) and have not (obviously) been discussed with htose now in charge.

Survey no:	287
worked best	
barriers	Funding issues with Health Authority.
further comments	Very difficult to answer questionnaire! We have different arrangements for different drugs and also different level of experience with individual care packages as we gradually taken them in house.
Survey no:	292
worked best	Chemotherapy - Palliative Care with 5FU
barriers	Cost of equipment
further comments	
Survey no:	297
worked best	
barriers	
further comments	We do not provide services at home for any patients.
Survey no:	300
worked best	Only had one patient who didn't want to be in hospital.
barriers	Patient was keen to visist a friend outside the area which made continuous treatment difficult.
further comments	Any patients from the area serviced by this hospital are seen and managed by the Teaching Hospitals in this area and the chemotherapy is managed by the local Oncology hospital and we have no involvement with these "hi-tech" treatments. This may well change if/when we become a cancer unit.
Survey no:	302
worked best	Our scheme is in it's infancy and we have only had one patient receiving IV infusions.
barriers	
further comments	
Survey no:	303
worked best	Home IV feeding. HIV - feeding and antibiotics - surprisingly good.
barriers	Delays from HAs accepting cost.
further comments	
Survey no:	304
worked best	
barriers	
further comments	

Survey no:	307
worked best	
barriers	
further comments	Treatments are initiated in the acute Trusts in Sheffield and therefore clinincal decisions have been made before patients are taken on by our Trust. problems tend to be referred back to the original prescribers. The service works as a partnership between the trusts and the GP's. Our Trust pharmacy is asked for advice from time to time and HAs been involved in some nurse training.
Survey no:	312
worked best	
barriers	
further comments	Telephoned 16.2.98. As this is a community trust I am having difficulty answering the questions. Some of these things are provided by community pharmacies, for others the patient would have to go into hospital. There is no Pharmacy here and the Trust purchase care from acute trusts nearby. We have 12 community hospitals and they may have different arrangements. I'll try and get hold of some answers for you.
Survey no:	317
worked best	Chemo - reduces inpatient stay.
barriers	Transport. Cost.
further comments	
Survey no:	321
worked best	Those who are young and motivated.
barriers	Political/financial primarily over who pays.
further comments	Different parts of the services provided are co-ordinated by different staff and it HAs taken a bit of effort to get the answers! Cytotoxics - currently there are no patients but our average for the last 12 months HAs been 6/week. Cancer Unit accreditation HAs advanced audit etc in that area. Cystics have to catch up. We have in the past provided domicillary narcotic analgesics for continuous infusion but this is now dealt with by GPs.
Survey no:	322
worked best	adult home TPN - careful patient selection, good patient education and training, patient motivation
barriers	Medical staff- most do not consider the option and are unaware of the types of home care available. Those that are do not understand the process of arranging contacts between the home care companies and the relevant Has.
further comments	The biggest problem is dealing with the HAs (often not our own) getting them to agree to pay for the treatment and set up the contract with the home care company. Medical staff do not appreciate the complexity of this process - they agree to send a patient home on treatment in the morning and expect it to be provided the same afternoon.

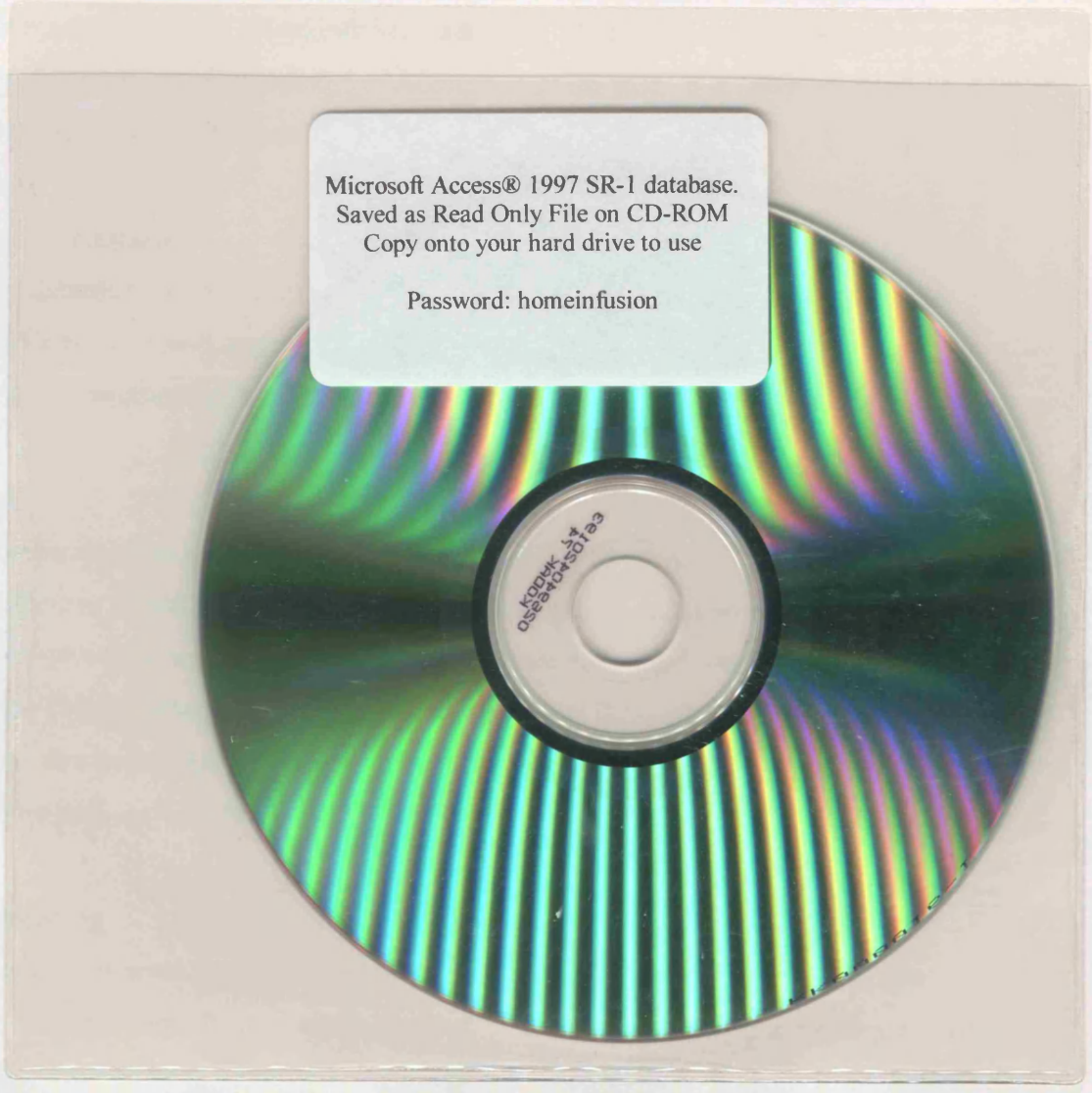
Survey no:	323
worked best	cystic fibrosis - already well established and a dedicated team available.
barriers	providing 24 hour back up, providing fridges and transport - too expensive to do ourselves therefore need part of service provided by commercial company. try and decrease drug costs by providing short courses and cheap drugs from hospital pharmacy as commercial companies charge a lot for this. Also save money by getting patient home quicker.
further comments	
Survey no:	327
worked best	adult TPN - more stable patient
barriers	cost! Complexity of managing system through internal market etc
further comments	
Survey no:	332
worked best	
barriers	
further comments	Providing hi-tech health care at home is an expanding field in this hospital especially for cystic fibrosis patients but as yet only represents a small number of patients. With the current programmes of care that are being developed, things are likely to take off in this area.
Survey no:	337
worked best	we only have experience of the two groups identified. However we have managed to make both of these work despite occasional hiccups. BCH - based service works best (Desferal) due to easier communication.
barriers	Ability of parents/families to cope. Liason with other hospitals, particularly when patients transfer from paediatric to adult services. Large geographical area. Purchasers NOT usually a problem!
further comments	No other comments at this stage. Please feel free to call for further information if required.
Survey no:	341
worked best	
barriers	
further comments	
Survey no:	344
worked best	TPN - those on a stable regimen, long-term -> bulk orders and deliveries. Cytos - those involving a 7 day infusion to save beds.
barriers	Cytos - transfer of funding to enable bed or day case savings to be used to purchase 7 day disposable pumps.
further comments	Services indicated are not provided as "hi-tech health care at home" as such see Q13 but are types of home treatment under the caree of this hospital therefore have been included. Hope this is of some use.

Survey no:	349
worked best	Only had 3 TPN patients.
barriers	Prior to EL(95)5 and even since - takes time to sort out financial aspects - agree budgets etc. Our first home TPN patient had to stay in hospital several months till sorted. Complicated by fact that he emigrated to another country then came back to Britain when foreign health insurance ran out and he had no home in the UK to be discharged to.
further comments	
Survey no:	352
worked best	Haematology myeloma patients having Doxorubicin/Vincristine 4 day continuous infusion via walkmed pump - pt found it most acceptible.
barriers	
further comments	
Survey no:	355
worked best	we only do one group
barriers	funding
further comments	Currently an MSc is auditing the home IV service should this study prove valid then permanent measures will be put in place.
Survey no:	359
worked best	We have not been providing these services for very long but at present all 4 services are success stories.
barriers	-lack of funding from the HA -difficulties in arranging delivery times and days.
further comments	
Survey no:	362
worked best	Home TPN, no success elsewhere due to lack of consultant specialist knowlege and funding issues.
barriers	Funding and organisation hold the whole area back.
further comments	As a Trust our only progress has been with TPN, out of necessity. Personally Home Care is woefully under- utilised because of the lack of infrastructure in the community and clinicain understanding that it is possible.
Survey no:	365
worked best	
barriers	
further comments	Answers to Question 2 refer to an individual patient planned for home TPN some years ago. Since then no patients have received TPN at home. Chemotherapy is only very occasionally given at home, and is treated on a 'one off' basis and arraned between the oncology nurse and pharmacy. There have been no such patients in the last year. Apologies for the delay. I have been trying to find out about cystic fibrosis patients as I am sure we have some. Unfortunately I have not found anyone who can answer these questions. This in itself probably indicates lack of any co-ordinated approach. Thanks.

Survey no:	368
worked best	chemotherapy or desferrioxamine by supplying patients with pharmacy filled elastomeric pumps.
barriers	patient selection, acceptability by district nurses to provide support
further comments	
Survey no:	373
worked best	n/a
barriers	
further comments	
Survey no:	999
worked best	HIV patients allows them maximum independence and patients normally show good compliance.
barriers	Increased cost of equipment, increased work for pharmacy in filling devices and problems with infusion devices.
further comments	Our number of HIV patients has dropped off dramatically
Survey no:	1005
worked best	No real problems with any group.
barriers	transport is sometimes (rarely) unreliable.
further comments	
Survey no:	2222
worked best	Parenteral home care
barriers	financial
further comments	

APPENDIX

25


Microsoft Access® 1997 SR-1 database.
Saved as Read Only File on CD-ROM
Copy onto your hard drive to use
Password: homeinfusion

APPENDIX

26

Worked Examples for Benchmarking Database

Instructions for use and worked examples.

The benchmarking tool is a Microsoft Access ® 1997 SR-1 database. It is designed so that users need to have no knowledge of Access to use the tool. It is however helpful to have an understanding of Microsoft Windows® software.

Opening the database

To use the database load the CD onto the CD drive of your computer. Open Microsoft Access and a window will appear, choose "open an existing database" and OK. Find the CD drive and open the file "benchmarking home infusions.mdb".

Password

A password is required to open the database, type in "homeinfusion". Note that the password facility would be very important when real patient data was stored and compliance with data protection laws and ensuring patient confidentiality would need to be assured. This database does contain some real patient data and some which is made up to illustrate a point. **All of the patient names and personal details are fictitious.** The database will open on the Main Menu Form.

Troubleshooting

If at any stage you press a grey button and nothing happens go to "tools" and choose "database utilities" then choose "repair database". You should then get a message to say that the database has been successfully repaired and you will be back at the Main Menu Form.

Worked examples

The database does not have a huge amount of data in it and therefore in order to demonstrate some of its functions it is necessary at this stage to direct the user to some

data that will seem meaningful. The following worked examples are referred to in chapter 4 and should be worked through at the appropriate point in the text.

1. **Example showing how definitions of clinical problems are shown for the user.**

- go to the main menu
- choose "add to or amend record of existing patient"
- choose "Stuart Donnington" from the drop down list
- press the "choose what to amend" button *(if this doesn't work go to tools database utilities and then repair database and start again then it should work)*
- press the "clinical evaluation" button, this will take you to the first of 7 clinical evaluation forms completed for this patient
- under "clinical problem" in a yellow box it says "infusion phlebitis grade 0" . The box underneath gives a definition of this.
- Use the drop down box to select other clinical problems and notice that the definition underneath refers to whichever you have selected.
- Reselect "infusion phlebitis grade 0"
- Press the "back to main menu" button

2. **Looking at patient details and choosing what data you want to enter for a patient**

- go to Main Menu
- choose "add to or amend record of existing patient"
- choose "Anne Green" from the drop down list
- note the use of the fields on this form
- press the "choose what to amend button"
- note how the information entered on the first form is carried through to other forms
- choose "prescription"
- you will see that Anne Green has had one prescription for a 5FU infusion

- you may choose to add a new prescription in which case the patient details will already be filled in and you have to select the drug and fill in the rest of the details. Do not start to do this as you must then complete all the appropriate fields.
- The next grey button allows you to "enter other information about this patient" pressing this takes you back to the menu where you can select other information that you wish to check or enter such as "incoming information". You will see that Anne Green has three forms completed with incoming information. Use the arrows at the bottom of the screen to go through them.
- You then have the choice of entering more information on that form, choosing to go to further details about Anne Green or going back to the main menu to choose another patient, go back to "Main Menu".

3. The discharge form

- go to Main Menu
- choose "add to or amend record of existing patient"
- choose "Stuart Donnington" from the drop down list
- click on "choose what to amend"
- click on "discharge" or press the character d on the keyboard
- you will see that Stuart Donnington has three completed forms for discharge, scroll through them using the arrows.
- The binoculars allow you to search forms for a particular date for example.
- You have the choice of entering or viewing more information for this patient or returning to the Main Menu
- Return to Main Menu

4. The venous access device and training forms

- go to Main Menu
- choose "add to or amend record of existing patient"
- choose "Stuart Donnington" from the drop down list
- click on "choose what to amend"

- click on "IV access device " or press the character v on the keyboard
- you will see that Stuart Donnington has three completed forms, scroll through them using the arrows.
- you will see that this patient has had one central line placed by a registrar, and two PICC lines both placed by consultant anaesthetists
- you have the choice of entering or viewing more information for this patient or returning to the Main Menu
- choose enter more information for this patient
- click on training or press the "t" key on your keyboard
- use the arrows to scroll through in the same way as before
- return to Main Menu

5. The prescription form

- go to Main Menu
- choose "add to or amend record of existing patient"
- choose "Stuart Donnington" from the drop down list
- click on "choose what to amend"
- click on "prescription" or press the character "p" on the keyboard
- you will see that Stuart Donnington has a prescription for 5-flurouracil as a continuous infusion over 14 days in saline.
- Return to main menu

6. Reports 1

- go to Main Menu
- select the "choose a report to view or print button" or press the "r" key.
- This will take you to the Report Menu
- Enter a start date- 01/01/97.
- The end date will default to today's date but may be overridden
- Press the button "overall incidence of clinical problems by benchmarking centre" or the "o" key. This will give you a report shown as a graph.

- Click on close to return to the Main Menu

7. Reports 2

- Go back to the report menu as described above then enter the same date and press the "incidence of infusion phlebitis by benchmarking centre" button or press the "p" key. This will give you a report shown as a graph.
- Click on close to return to the Main Menu

8. Reports 3

- Go back to the report menu as described above then enter the same date and press the "incidence of clinical problems by IV access device and benchmarking centre" button or the "o" key. This will give you a report shown as a graph.
- Click on close to return to the Main Menu

9. Reports 4

- Go back to the report menu as described above then enter the same date and press the "show all prescriptions for a patient" button or the "s" key.
- The computer will ask you to input your centre ID, type 3.
- Then you will be asked for the patient number, type BL00066
- This will give you a summary report of all the prescriptions in the database for that patient.
- Click on close and then cancel to return to the Main Menu

APPENDIX

27

CENTRAL HOMECARE LIMITED
Unit 6, Grove Park, Mill Lane, Alton, Hampshire GU34 2QG
Telephone: (01420) 543400 Fax: (01420) 544588

PRESCRIPTION REQUIREMENTS
CENTRAL HOMECARE COPY

Patient's Name _____

Date of Birth _____

Current Weight _____kg Sex F M

Patient's Address _____

_____

_____

Tel. No. _____

Name of carer _____

Carer's relationship _____

Order Number _____

Consultant _____

Hospital _____

please use hospital stamp

GP's Name and Address _____

_____

Tel. No. _____

Health Authority _____

To Central Homecare Limited,

Please supply the following for the above named patient:

Name of Drug	Dosage	Diluent	Volume	Duration of Infusion	Frequency	Length of Course	Type of Infuser

Special Instructions _____

_____

Name of Bolus Drug	Dosage	Frequency	Length of Course	Pre-filled Syringes *(tick if required)*

Name of Flush	Strength	Volume	Frequency	Pre-filled Syringes *(tick if required)*
Heparin				
Sodium Chloride	0.9%			
Hepsal / Heplok	10 units/ml			
Hep-Flush	100 units/ml			

Type of Venous Access

Consumables Y N

Delivery Date

Therapy Start Date

Time of 1st dose

Delivery Address (please tick *one* box and complete further information if applicable)

- ☐ Home
- ☐ Hospital _____
- ☐ Other _____

Please fax the completed form to Central Homecare and then post the top copy using the reply-paid envelope as soon as possible.

THANK YOU

Doctor's Signature	Doctor's Name	Pharmacy (optional)	Date

APPENDIX

28

The current position in England concerning home-based ambulatory infusion provided under EL(95)5

By J. Loader and G. J. Sewell

The apparent lack of knowledge of hi-tech health care at home by the bodies charged with responsibility for purchase is of concern, as is the absence of monitoring of contracts. This could result in poor patient care

Introduction Treatment of patients at home with intravenous therapies such as antibiotics, parenteral nutrition (HPN), chemotherapy and chelating agents has become widely accepted as a safe and effective model of health care.[1] Few problems have arisen and complication rates have been shown to be low.[2] Treating these patients at home offers benefits for hospitals through earlier discharge of patients, freeing-up hospital beds and improved cost effectiveness.[3]

EL(95)5[4] instructed health authorities in England to make provision through their contracts to support patients at home whose treatments included the delivery of drugs together with other products and equipment needed to administer them, typically provided as packages of care. The pharmaceutical advisers, medical advisers and contracts managers of health authorities were responsible for the implementation of EL(95)5 together with contracting and strategic planning for home-based patient care.

The aim of the project was to establish the current position in England on the purchasing of hi-tech health care at home (HTHH) by health authorities.

A questionnaire was designed to elicit the required information from health authority pharmaceutical advisers and medical advisers.

Methods A detailed, fully referenced literature review was prepared and questionnaire design techniques studied.

Regional directories for 1997/98 listing all the health authorities, trusts and community health councils in each region were obtained from the NHS Executive.

A health authority questionnaire was drafted, designed for administration to pharmaceutical advisers, medical advisers or contracting managers of health authorities to determine: which disease states are included in HTHH programmes; to what extent patients are being treated in their homes with "hi-tech" therapies; who is currently providing the various aspects of their care and how much is being invested in caring for these patients at home nationally.

The questionnaire was piloted at a regional meeting of pharmaceutical advisers. A letter was enclosed asking for the recipient's comments on the questionnaire's content and design. These resulted in minor changes to the final questionnaire and distribution in person.

From the Department of Pharmacy, Plymouth Hospitals NHS Trust and Postgraduate Medical School, University of Plymouth

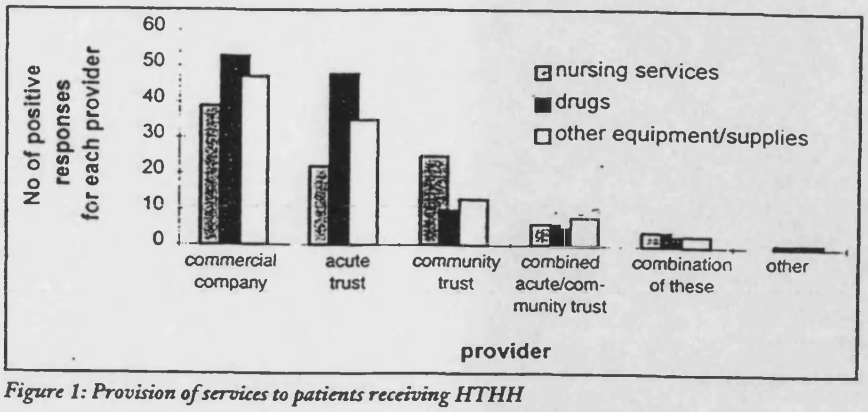


Figure 1: Provision of services to patients receiving HTHH

Between May and November 1997 the researcher was able to attend regional meetings of pharmaceutical advisers. Questionnaires and prepaid return envelopes were distributed by the researcher, where possible, with an explanation of the aims and objectives of the project.

Responses to the questionnaire were recorded on an Access database which was subsequently used in the analysis of the results.

Results Responses were received from 87 of the 100 health authorities; 27 out of 87 (31%) were unable to answer any questions regarding the number of patients under their jurisdiction receiving hi-tech health care at home or provide information on the cost of their treatment.

The percentage of health authorities treating one or more patients with the following; home therapies were: TPN 54%, antibiotics for cystic fibrosis 46%, desferrioxamine 25%, antivirals for HIV 10% and chemotherapy 5%.

Other hi-tech therapies given at home included terbutaline for asthma, immunoglobulins, enzyme replacement for Gaucher's disease, prostacyclin and beta-interferon.

Commercial home care companies and acute trusts were found to be the main providers of all aspects of HTHH (Figure 1).

Only 17 out of 87 (19%) health authorities had any future plans for the care of these patients. One of the 87 health authorities knew of any fund-holding GPs who directly purchased HTHH for their patients.

Respondents were asked open questions on which aspects of HTHH had been successful and which aspects had proved difficult or problematic.

Comments regarding success included the fact that the health authority has been able to shift the responsibility for contracting for HTHH on to the hospital trusts and the contracting process enabled them to achieve better quality of care or cost effective care for the patients. Some health authorities see the trusts as better placed to contract for these services.

Difficulties included problems with the initial implementation of EL(95)5, funding of new patients, as there are no new monies available, problems with tertiary centres and extra-contractual referrals, and not knowing whose responsibility the monitoring, audit and evaluation of the service is.

Discussion This survey has highlighted the complexity of the current contracting procedure for hi-tech health care at home under EL(95)5. Some health authorities have invited tenders to provide the service, while others have either continued with arrangements in place before EL(95)5 or passed on the responsibility to the local trusts. From these data it appears that commercial home care companies have the largest share of the home care market in England closely followed by NHS trusts. District nurses working for community trusts are caring for patients receiving HTHH in some areas of the country. Intravenous antibiotics for cystic fibrosis and home TPN are the major infusions being provided in the domiciliary setting. It is unclear who is monitoring the quality of service received by patients.

The apparent lack of knowledge of HTHH by the bodies charged under EL(95)5 with responsibility for purchase is of concern as is the absence of monitoring of contracts highlighted by the qualitative data. This could result in poor patient care. In order to establish the full picture regarding HTHH in England it is necessary to obtain information from all providers of "hi-tech" home care, ie, commercial home care companies and trusts. This is the subject of further work of this project.

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APPENDIX

29

Antibiotic treatment accompanying surgery for appendicitis

By T. L. Rose, K. Hatfield, B. Hebron, J. F. Marriott and K. A. Wilson*

Introduction Reducing inappropriate antibiotic prescribing is currently a major issue in the drive to reduce the spread of antibiotic resistance.[1] Appendicitis is common, rarely associated with concurrent conditions and is often complicated by infection. However, accurate diagnosis is often made only after surgery and any antibiotic treatment should reflect this diagnosis.[2] The present study describes an audit of antibiotic use associated with appendectomy.

Methods The medical histories of all patients who underwent appendectomy between April, 1997, and March, 1998, at City Hospital NHS trust were reviewed retrospectively. Data were directly entered into a relational database for manipulation and analysis. Data were collected on duration of in-patient stay, histological diagnosis, antibiotics administered, including frequency, route and duration. Patients with co-morbidity were excluded from this analysis.

Results Medical histories from 146 patients were included for analysis. Following operation 40 had histologically normal appendix, 64 non-perforated acute appendicitis and 42 severe appendicitis presenting as abscess formation, perforation and gangrenous appendix. The results from the present study are summarised in Table 1.

*Pharmacy practice group, school of pharmacy, Aston university, Birmingham; *City Hospital NHS trust, Birmingham*

TABLE 1: SUMMARY OF ANTIBIOTIC TREATMENT FOR PATIENTS WHO UNDERWENT APPENDECTOMY

	Patients			Numbers treated			Antibiotic duration (days)		
	No	Infected	Stay	IV	Oral	TTO	IV	Oral	TTO
Normal	40	4 (10)	4	23 (58)	14 (35)	8 (20)	2	2	5
Appendicitis	64	6 (9)	5	58 (91)	36 (56)	28 (44)	3	2	5
Severe appendicitis	42	12 (29)	6	41 (98)	27 (64)	27 (64)	4	2	6

No = number of patients; stay = duration of hospitalisation (days); IV = intravenous; TTO = discharge medication. Figures in parentheses are percentages

Discussion As might be expected, the length of hospital stay, duration of IV antibiotic administration and total period of antibiotic cover correlate with the severity of the condition. However, although similar infection rates were observed in those patients found to have a normal appendix and those with acute appendicitis, patients in the latter group received more aggressive antibiotic therapy, notably by the IV route. The underlying reasons for these findings are being explored currently in order to improve cost-benefits in this area of practice.

Moreover, since the conditions described are embraced by clear formulary guidelines supported by medical microbiologists, it is suggested that postoperative antimicrobial prescribing might be best accommodated by a dependent prescribing pharmacist in accordance with the recommendations made in the recent Crown report.[3] Implementation of this latter concept might further improve antibiotic prescribing, by facilitating conversion from IV to oral routes and reducing the total duration of antibiotic course.

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The role of the pharmacist in the provision of hi-tech health care at home (HTHH)

By J. Loader† and G. J. Sewell*‡*

Introduction In the United States pharmacists have developed an important role in the establishment of HTHH schemes,[1-3] especially in ensuring that quality and continuity of home health care is consistent with that provided to inpatients.[2] The UK has been slow to implement home infusion programmes but, with pressure on hospital beds and increasing experience of HTHH, it is becoming accepted as a safe and effective model of health care, although there is still a need for more descriptive studies.[4] HTHH fits the Government agenda, laid out in the recent White Paper,[5] of making health care easily accessible to patients, as close to home as possible. The aim of this study was to determine the current place of pharmacists in the provision of HTHH in England. These data would identify areas where their role could be extended or modified to optimise pharmaceutical care for HTHH patients.

**Plymouth Hospitals NHS trust; †Plymouth postgraduate medical school, Plymouth university; ‡department of pharmacy and pharmacology, Bath university*

Method Lists of all NHS trusts in England were obtained from NHS Executive regional directories. Ambulance, mental health and learning disabilities trusts were excluded from the survey. A questionnaire was designed based on roles of the pharmacist reported in the literature and from local experience of providing HTHH. It was piloted by seven pharmacists with experience of HTHH. A telephone survey of 349 trusts, over the period November to December, 1997, was carried out to establish which pharmacy departments were involved with HTHH schemes. The written questionnaire was sent to those with any involvement (167). Responses were recorded on an Access database which was subsequently used for analysis of the results.

Results One hundred and five responses were received (63 per cent), of which 94 were evaluable. The roles which pharmacists most frequently undertook in HTHH (≥67 per cent) are listed in Table 1. The areas where pharmacists had least input were in maintenance of the infusion pump (19.1 per cent), competency assessment of the patient/carer (20.2 per cent) and selection of venous access device (22.3 per cent). There were 64 pharmacists (68.1 per cent) who had been involved with setting up a HTHH programme, but only eight were "very involved" with monitoring quality of the HTHH service while 32 had "some involvement" and 44 said they had "no involvement" (nine did not answer and one answered "n/a"). Fifty-nine pharmacists had been involved with setting service specifications and 30 had "no involvement" (five gave no answer). Fewer (39) were involved with ensuring compliance with the service specifications than setting them and 44 had no input at all (11 did not answer this question).

Discussion In England hospital pharmacists apply to HTHH their traditional roles of

TABLE 1: MOST COMMON AREAS OF PHARMACIST INVOLVEMENT IN HTHH PROGRAMMES

Role of the pharmacist	Number of pharmacists giving response				
	Very involved	Some involvement	No involvement	No answer	Total
	(a)	(b)			(a+b)
Pharmaceutical advice to prescriber	58	26	7	3	84 (89.4%)
Co-ordination and communication with other health professionals	41	41	9	3	82 (87.2%)
Providing formulation and stability data	62	19	10	3	81 (86.2%)
Maintenance of prescription records	55	21	13	5	76 (80.9%)
Co-ordination and communication with patients and their families	19	56	15	4	75 (79.8%)
Supply of drugs	55	15	21	3	70 (74.5%)
Aseptic reconstitution of drugs and filling of infusion devices/syringes	54	16	19	5	70 (74.5%)
Choice of appropriate drug therapy	32	37	22	3	69 (73.4%)
Co-ordinating the home care program	25	38	26	5	63 (67.0%)
Setting up the HTHH program	35	28	26	5	63 (67.0%)

providing advice, specialist knowledge, communicating with patients and other staff and in providing drugs. More than half of the pharmacists giving a response had no involvement in quality assurance of the home care programme even though 64 were involved with setting up the programme. This contrasts markedly with the US situation.[1-3] It has been shown that this role of monitoring quality has not been taken on by health authorities as purchasers of HTHH.[6] With the recent emphasis on clinical governance, pharmacists working in HTHH in England should examine the monitoring and quality roles of their US colleagues and determine whether contracting and service delivery of HTHH in the UK health care system could also benefit from increased pharmacist input. One limitation of this study is that some trusts provide the entire package of care to patients at home whereas others contract for some aspects with a commercial provider, necessitating varying levels of pharmacist input. Future development of the role of pharmacists in HTHH should include assurance and monitoring of the quality of care delivered by both commercial and NHS providers.

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Continuing professional development for pharmacists: a strategic approach

By Claire Grout, Jenny Dorey and Jane Hough

Introduction Recruitment and retention are crucial issues in hospital pharmacy at present and are likely to worsen with the "fallow year" approaching. A recent survey has shown that 13.7 per cent of all pharmacist posts were vacant in NHS hospitals in England, Wales and Scotland in July, 1998.[1] Recruitment and retention difficulties have led to reductions in service, or refusal of requests for new services, in half of all hospitals. The Berkshire and Oxfordshire continuing professional development (CPD) project was established to support individual development of pharmacists, in line with departmental needs, as an aid to recruitment and retention. A pharmacist was appointed to lead the project, with funding from the Berkshire and Oxfordshire Education Consortium.

Method Following discussion with the project steering committee (representatives from each trust involved in the project), a pilot study was performed. Ten pharmacists were recruited, ranging from B to F grade, and representing a variety of different roles within hospital pharmacy. Each pharmacist developed a portfolio of evidence of achievement and highlighted development needs, related to a series of criteria. These criteria, developed after discussion with a number of practitioners, were designed to be applicable to all pharmacists. In discussion with the project pharmacist, a personal development plan was produced, which was approved by the line manager. The process was evaluated by a structured interview with each pharmacist.

Oxford Radcliffe Hospitals NHS trust

Results A number of different activities were included on the personal development plans, such as courses, reading and working through case studies or questions, shadowing, or undertaking new tasks. The project pharmacist identified suitable material wherever possible. All pharmacists involved in the pilot study found the process very helpful and motivating. They all felt that a mentor was needed to facilitate the process and provide ideas for development. Although there had been some initial concern regarding the time needed for the process, this was not found to be a problem, particularly as they became more reflective in their approach.

Discussion The Government has reinforced the importance of CPD in achieving good clinical practice.[2] The project described is working towards achieving this aim for pharmacists. With modification to the portfolio structure and the criteria following feedback from the pilot study, the project will be rolled out to all hospital pharmacists in the area. Each personal development plan will be linked to individual appraisal and objectives. The project pharmacist will act as mentor to all pharmacists, liaising with each individual's line manager. It is suggested that for new posts individuals are appointed on flexible grading, so that a pharmacist has the opportunity to develop to a higher grade within the post, linked to objective criteria.

Enthusiasm in the project is encouraging and it is hoped that the motivation provided by individual continuing development will promote retention of staff.

ACKNOWLEDGMENT: Thanks to the Project Steering Committee, the pilot study participants, and the Berkshire and Oxfordshire Education Consortium for their support.

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APPENDIX

30

PHARMACY ABROAD

Survey of home infusion care in England

JILL LOADER, GRAHAM SEWELL, AND SHIVAUN GAMMIE

Am J Health-Syst Pharm. 2000; 57:763-6

The Pharmacy Abroad *section of* AJHP *features brief, informal, and topical communications related to pharmacy in other countries. Contributions are welcomed from pharmacists abroad or from pharmacists who have traveled abroad.*

AJHP *also encourages pharmacists from outside of the United States to submit traditional manuscripts (e.g., scientific studies, descriptions of practice innovations), which are evaluated for publication in the primary sections of the journal.*

The National Health Service (NHS) was founded in 1948 by the government of the United Kingdom on the principle that the care it provided would be available to all, irrespective of means, on the basis of need and that most services would be provided free of charge at the point of use. The NHS is funded through national income taxes. Government health policy is implemented through the Department of Health (run by elected officials led by the Minister for Health, who reports directly to the Prime Minister) and is managed by the NHS Executive (run by appointed civil servants). The NHS Executive has eight regional offices that manage the 100 Health Authorities (HAs) in England.

During the late 1980s, HAs were given the resources to purchase health care for their local populations. The resources were to cover health promotion, public health, and all health care provided in the community and through hospitals. Providers of health care competed for contracts to deliver their services. (The NHS is currently undergoing a reform that will move responsibility for purchasing health care from the HAs to primary care.)

Physicians (general practitioners, or GPs) and health care professionals working in the community are the public's primary access to health care (primary care). GPs may refer their patients to specialist physicians in hospitals (secondary care), who in turn may seek advice from specialty hospitals (tertiary referral centers).

Acceptance of home infusions has been slow in England because of the way health care is funded through the NHS, the lack of incentives to change current practice, and the existence of other priorities.[1] There is no direct cost to the patient or an insurer when a patient is admitted to the hospital, and therefore there is no direct financial pressure from them to reduce the length of stay.

Before 1995, some GPs prescribed infusions for their patients and some home infusions were organized and paid for via secondary or tertiary care (the hospitals, or NHS trusts). In 1995, the government issued a directive that instructed HAs to buy packages of care for patients at home whose treatments included "the delivery of drugs together with other products and equipment needed to administer them" (e.g., total parenteral nutrition [TPN], intravenous antimicrobials, and antineoplastic agents).[2] The HAs contracted only for those patients for whom GPs were previously prescribing drugs; hospitals continued to pay, out of their own budgets, for patients they were already treating with home infusions.

The objective of this study was to collect information on the purchasing and provision of home infusions in England. Specifically, we sought to identify

- The indications for home infusions,
- The number of patients receiving home infusions,
- The contract mechanisms,
- The providers of various elements of home infusion care,
- The geographic distribution of patients receiving home infusions, and
- The mechanisms for monitoring quality and outcomes.

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Methods. Surveys were conducted of all the purchasers and providers of home infusion care in England for the period from April 1997 to December 1998. We visited regional meetings of pharmaceutical and medical advisers of the 100 HAs to explain the objectives of the project and to distribute written questionnaires on the purchasing of home infusions. We conducted a telephone survey of all the hospitals in England (excluding those specializing in mental health and learning disabilities) to establish which were involved in caring for patients receiving home infusions. This was followed up with a written questionnaire to elicit further information from those who did purchase or provide home infusions for their patients. Finally, we sent a written survey to the six commercial providers of home infusions in England. This questionnaire was designed in conjunction with members of the industry, who advised us on what information the companies might be willing to share in this commercially sensitive area.

The anonymity of all survey participants was ensured to encourage frank reporting.

Results. *Indications for home infusions.* The main indications for home infusions in England were administration of TPN for Crohn's disease and short-bowel syndrome, antimicrobial agents for cystic fibrosis, antineoplastic agents (continuous infusions), deferoxamine for thalassemia, and antivirals for HIV infection.

Table 1 shows the percentage of responding HAs and hospitals providing home infusions for patients under their jurisdiction. The hospitals were more likely to provide antineoplastic agents and antivirals for HIV infection than the HAs, but the HAs more commonly had contracts for providing home TPN than the hospitals. The reason is probably that fewer GPs were prescribing antineoplastic agents and antivirals for their patients before the 1995 government directive.[2]

Number of patients. In many cases, neither the hospitals nor the HAs were able to specify the number of patients receiving home infusions. While an HA may take on responsibility for contracting for the provision of, for example, home parenteral nutrition for the patients in its area, it may leave the provision of other types of home infusions, such as infusions of antineoplastics or deferoxamine, entirely to the local hospital (Table 1). The HA may not even be aware that patients are being treated at home with such other infusions.

It was not easy to interpret the results for patient numbers. When the question was left blank, this could have meant either (1) that no patients were being treated at home with that drug or for that condition or (2) that the participant did not know if there were any of these patients.

The largest numbers of patients had their care either supplied or purchased by hospitals (Table 2). The largest numbers of patients were receiving antineoplastic agents or antimicrobial agents for cystic fibrosis; far fewer were receiving home TPN infusions, although the largest expenditure was on adult and pediatric home TPN.

Contract mechanisms. HAs generally have bulk contracts with local hospitals for providing specified services in order to avoid the large administrative costs of individually billing for every service provided. Less than half (46%) of the HAs purchased home infusions under a separate contract. One quarter (26%) added the money, taken from GPs' budgets, to their bulk contracts with the hospitals and left it to the hospitals to purchase or provide home infusions. Fifteen percent used a separate contract for some drug products and a bulk contract for oth-

Table 1.
Percentage of Health Authorities and Hospitals Providing Home Infusions

Indication	No. (%) Respondents Providing Home Infusions[a]	
	Health Authorities	Hospitals
Administration of antimicrobials for cystic fibrosis	40 (46.0)	43 (45.7)
Antineoplastic therapy	5 (5.7)	39 (41.5)
Administration of antivirals for HIV infection	9 (10.3)	14 (14.9)
Total parenteral nutrition administration	47 (54.0)	41 (43.6)
Deferoxamine administration	22 (25.3)	30 (31.9)
Administration of enzymes for Gaucher's disease	5 (5.7)	5 (5.3)
Administration of immunoglobulins	2 (2.3)	5 (5.3)
Administration of terbutaline	2 (2.3)	2 (2.1)
Pain relief	0 (0)	5 (5.3)
Administration of epoprostenol	2 (2.3)	1 (1.1)
Administration of antimicrobials for other indications	0 (0)	8 (8.5)

[a]Responses citing any number of infusions greater than zero were counted.

Table 2.
Number of Patients Receiving Home Infusions

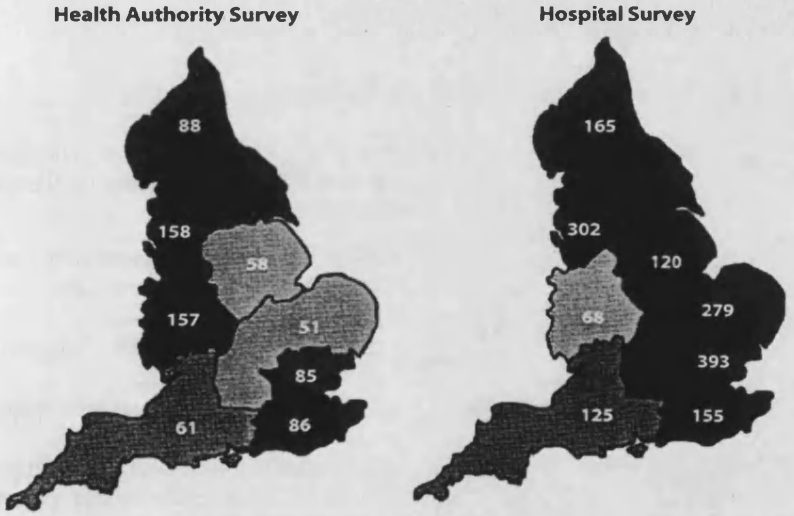
Indication	No. Patients[a]	
	Health Authorities	Hospitals
Administration of antimicrobials for cystic fibrosis	446	879
Antineoplastic therapy	33	990
Administration of antivirals for HIV infection	25	83
Total parenteral nutrition administration	234	449
Deferoxamine administration	114	264

[a]Numbers are normalized (divided by percent response rate and multiplied by 100).

Table 3.
Providers of Specific Elements of Home Infusion Care

Element of Care and Provider	No. (%) Respondents	
	Health Authorities	Hospitals
Drugs		
Hospital pharmacy	63 (52.5)	160 (68.4)
Commercial company	53 (44.2)	68 (29.1)
Community pharmacy	0 (0)	5 (2.1)
Other	4 (3.3)	1 (0.4)
Nursing care		
Hospital	22 (22.9)	143 (62.4)
Commercial company	39 (40.6)	30 (13.1)
Community hospital or district nurses	25 (26.0)	48 (21.0)
Other	10 (10.4)	8 (3.5)
Equipment and supplies		
Hospital	35 (32.7)	134 (61.5)
Commercial company	47 (47.0)	72 (33.0)
Primary care or community hospital	13 (12.1)	5 (2.3)
Other	12 (11.2)	7 (3.2)

Figure 1. Geographic distribution of patients receiving specified types of home infusions in England.



ers. Very few HAs have used bidding for the purchase of home infusions.

Comments submitted by hospital pharmacists indicated that there is a lack of coordination in the hospitals with respect to the purchasing and provision of home infusions. One pharmacist wrote, "The situation is very complex—diffuse and vague accountability—very fragmented. In short, a mess!" Another stated, "I have been trying to find out about cystic fibrosis patients, as I am sure we have some. Unfortunately, I have not found anyone who can answer these questions."

The commercial providers of home infusions stated that care for all home infusions was more often purchased by a hospital or HA on an individual-patient basis than under a contract.

Providers of various elements of home infusion care. Table 3 gives the distribution of providers of medications, nursing care, and equipment and supplies for patients receiving home infusions. The hospitals were the major suppliers of all three when care was purchased or provided by hospitals. Even when the HAs purchased care, the hospitals were still the major providers of drugs and nursing care (closely followed by commercial home care companies); commercial providers most frequently provided equipment and supplies.

The HAs were more likely than the hospitals to purchase a package of care for home infusions from a commercial provider. There was significant input from district nurses (primary care) in providing nursing care for patients receiving home infusions.

Geographic distribution. Figure 1 shows the geographic distribution of patients receiving five specified types of home infusions in the eight regions of the NHS. There was geographic variation in the number of patients being treated with home infusions, and the HAs generally purchased care for fewer patients than the hospitals.

Quality- and outcomes-monitoring initiatives. Twelve HAs expressed concern over the lack of auditing of the quality of patient care, and 11 said they had no way of knowing whether they were getting value for their money. Only 18 (19.1%) of 94 hospitals said they had an audit system for measuring the quality of care, and only 12 (12.8%) had an audit system for measuring patient outcomes.

Five of the six commercial home care providers in England were not aware of any HAs or hospitals with whom they had contracts having any audit systems for measuring patient outcomes or benchmarking their services against those of other providers. Four were aware of contract HAs or hospitals having audit systems for measuring their services against agreed-upon service specifications or for monitoring the services they provided.

One commercial provider stated, "Virtually all our business is noncontractual. Often patients are tendered for individually but in a nonformal

fashion (i.e., hospitals ring for quotes and usually go for the cheapest!)."

Discussion. Home infusions are gaining acceptance in England, but not uniformly. This may reflect differences in the geographic distribution of the conditions being treated.

There are many mechanisms for purchasing and providing home infusions in England. It is not uncommon for home infusions to be provided on an ad hoc basis. This makes it difficult to obtain a clear and accurate picture of the home infusion market. It was impossible in this study to obtain information from all of the many health professionals who may be involved in the provision of home infusions.

The percentage of HAs providing home infusions was smaller than that found in a telephone survey by other researchers,[3] possibly because we requested more detailed information in our written survey and because our survey was directed at different professionals within the HAs.

The lack of monitoring of the quality of care received by patients at home and of their clinical outcomes is of concern. Most purchasers are not monitoring their contracts for quality, and providers are not required to demonstrate continuous quality improvement or even a minimum level of service.

The current restructuring of England's NHS creates an opportunity to review the mechanisms used to purchase and provide home infusions. A system whereby all home infusions are purchased via the same mechanism would seem a sensible first step. Quality and outcomes monitoring should be urgently addressed.

Conclusion. A survey of home infusion care in England found deficiencies in coordination of services, quality control, and outcomes monitoring.

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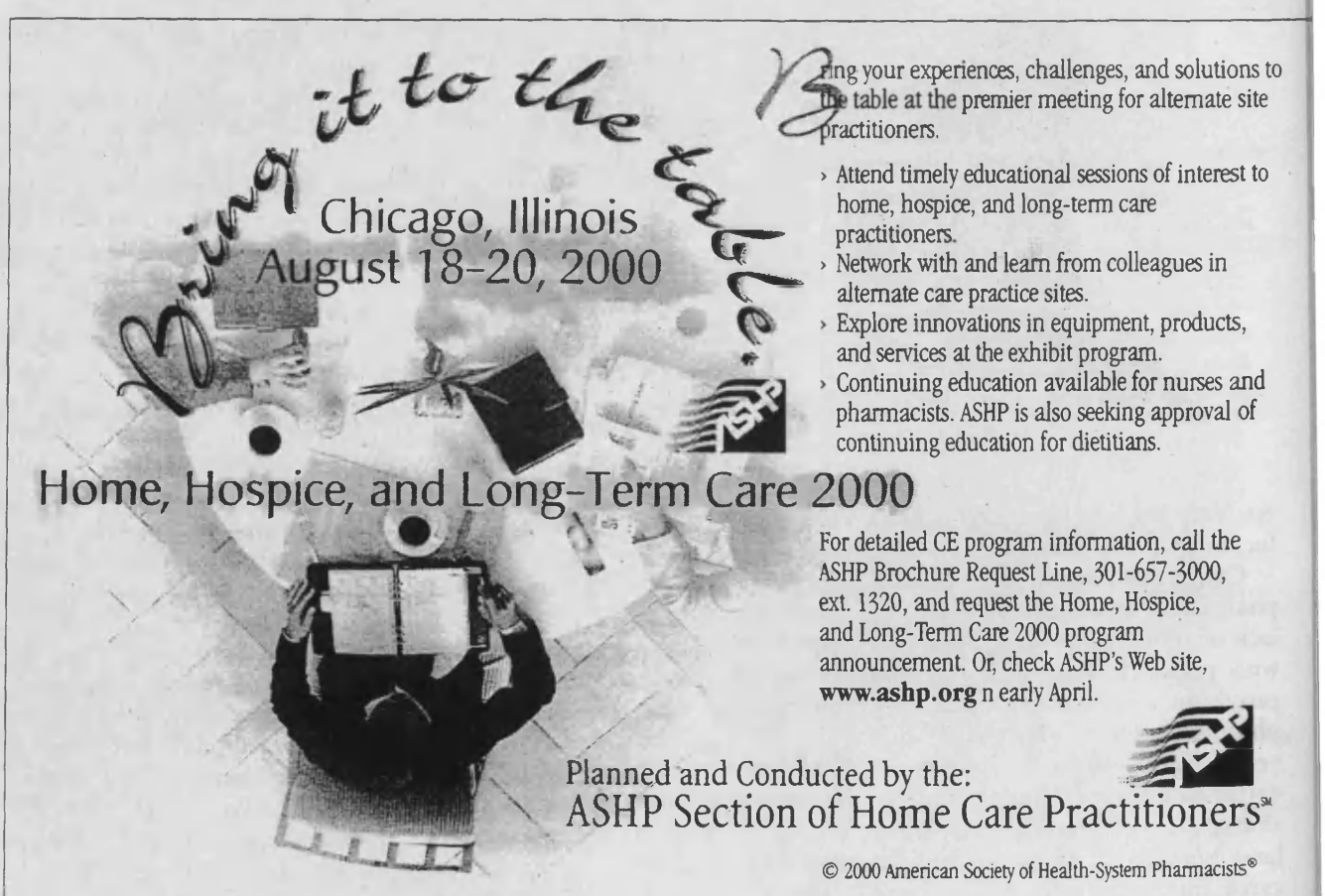

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